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Embodied Precarity:
The Biopolitics of AIDS Biomedicine in South Africa

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Submitted for the Degree of Doctor of Philosophy

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i. Declaration

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

Signature:

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iii. Acronyms

ABIA – Associação Brasileira Interdisciplinar de AIDS
 ACTA – Anti-Counterfeiting Trade Agreement
 ANC – African National Congress
 ANT – Actor Network Theory
 ART – Antiretroviral Therapy
 ARV – Antiretroviral
 AZT – Zidovudine
 BCM – Black Consciousness Movement
 BRICS – Brazil, Russia, India, China and South Africa
 CCT – Conditional Cash Transfer
 CD4 – Cluster of Differentiation
 CHC – Community Health Clinics
 CHW – Community Health Worker
 CL – Compulsory License
 d4T – Stavudine
 DTI – Department of Trade and Industry
 EE – Equal Education
 EFV – Efavirenz
 EPA – Economic Partnership Agreements
 ET – Equal Treatment
 FDC – Fixed Dose Combination
 FTA – Free Trade Agreement
 HAART – Highly Active Antiretroviral Therapy
 HSL – Household Subsistence Level
 IG – Income Generation
 IP – Intellectual Property
 MMC – Male Medical Circumcision
 MSF – Médecins Sans Frontières
 NACOSA – National AIDS Coordinating Committee of South Africa
 NAP – National AIDS Programme
 NDoH – National Department of Health
 NRTI – Nucleoside Reverse Transcriptase Inhibitors
 NtRTI – Nucleotide Reverse Transcriptase Inhibitors
 NVP – Nevirapine
 PLWH – People Living with HIV
 PMA – Pharmaceutical Manufacturers' Association
 PMTCT – Prevention of Mother to Child Transmission
 PrEP – Pre-Exposure Prophylaxis
 RDP – Reconstruction and Development Programme
 sdNVP - Single Dose Nevirapine
 SJC – Social Justice Coalition
 SPLT – Substantive Patent Law Treaty
 SPT – Saúde Para Todos
 SUS – Sistema Único de Saúde
 TAC – Treatment Action Campaign

TDF – Tenofovir Disoproxil Fumarate
TLP – Treatment Literacy Programme
TLP – Treatment Literacy Practitioner
TPPA – Trans Pacific Partnership Agreement
TRC – Truth and Reconciliation Commission
TRIPS – Trade Related Aspects of Intellectual Property Rights
UCT – University of Cape Town
UFPE – Federal University of Pernambuco
VCT – Voluntary Counselling and Testing
WHO – World Health Organisation
WTO – World Trade Organisation

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UNIVERSITY OF SUSSEX

ELIZABETH ANNE MILLS

EMBODIED PRECARITY: THE BIOPOLITICS OF AIDS BIOMEDICINE
IN SOUTH AFRICA

SUMMARY

This thesis centres on the lives of women who live in Khayelitsha and who receive AIDS biomedicines through South Africa's public health system. It is tiered across five ethnographic chapters to elucidate a single overarching argument: biopolitical precarity is networked into the permeable body. This argument is based on ethnographic research and seeks to challenge the discursive construction of distance that divorces women's lives and bodies from the governance of AIDS biomedicines as life-giving technologies.

The multi-sited ethnography underpinning this thesis was configured to follow the networked threads that weave women's embodied precarity into the governance of technologies and the technologies of governance. To this end, fieldwork was conducted in South Africa from October 2010 – July 2011 in order to understand the embodied and political dimensions of access to AIDS biomedicine. Thereafter, fieldwork was conducted in Brazil from August 2011 – September 2011 to explore the networked connections spanning activist organisations, government coalitions and economic blocs to move out from the intimate spaces of women's lives and bodies to locate them in the regional and global spaces of biomedical developments and health policy dynamics.

This thesis argues that although it is crucial to anchor technologies in people's lives, it is also analytically and politically necessary to link people's lives - and the technologies that sustain them - back into the global assemblage that is networked around the governance of medicine. Therefore, I locate biomedical technologies in social and political contexts of lives of the people with whom I worked in Khayelitsha, and I argue further that their lives also need to be understood as part of a complex network of actors (spanning international organisations, regional coalitions and national governments) and actants (HIV and ARVs) that assemble in dynamic configurations and that are woven into and through the body.

1. Introduction

The shebeen's corrugated iron walls were the same blue as the brutal skies that arch over Khayelitsha in winter.¹ In this part of Khayelitsha, called Nkanini, homes were built on top of the sand. Like the shebeen, their windowless walls were made from cardboard posters and sheets of corrugated iron. One of the shebeen's three co-workers had painted larger-than-life bottles of beer along the rippled wall with painstaking precision. Each bottle a bright rendition of the real thing that, along with the pumping bass beating in my body, brought Nkanini's residents in to drink. We walked on, under snaking electricity wires, around Nkanini's single tap and over the muddy veins that leaked down the dusty road.

"This way sana, remember?" said Miriam as she looped her arm through mine.² We turned left after the tap and shuffled along a short alley, our bodies bumping into each other and the shack walls and wire fences that lined our route; against our sturdy bodies, these markers of home felt fragile. We turned right, left, and finally right into her garden where Masiphiwe, Miriam's 23 year old brother, was washing clothes over a large metal tub. We had last seen each other a few days before when the three of us had become lost searching for paraffin heaters. Miriam did not have electricity and refused to use the stolen supplies that snaked around her home; risk of electrocution rendered the benefit of warmth too precarious. The seasons were changing and it was getting too cold to rely on the sun to dry the bowls, her principal source of income, that she made from paper and glue; too cold to keep her chronic backache at bay. I first met Masiphiwe through a series of photographs in which he was wrapped in a ceremonial blanket, wearing formal pants and toe-capped shoes, a cap shielding his eyes. His body and all he wore signified Masiphiwe's transition to manhood; he had just returned from a traditional circumcision ceremony in the Eastern Cape, Miriam's family's rural home. On his return, he had stopped sharing the household chores and Miriam had berated the ceremony, saying, "He is practising his manhood on me". On this day, Miriam was pleased with her brother. We left Masiphiwe and walked through the door where Miriam had written, "Please do not vandalise my home! I'm begging you". This was a message to Miriam's 25-year-old brother, Lwandle, who worked in the shebeen. In a fit of anger at Miriam's refusal to give him money, he had attacked her home with his fists and a metal rod. The violence

¹ A name for (legal and illegal) pubs in South Africa.

² An isiXhosa word meaning 'dear'.

imprinted in the battered door spoke to a broader web of precarity in Miriam's life and echoed a series of photographs that Lwandle had taken on her camera, which he later stole; in these photos he posed with the shebeen's owner and artist, their shirts unbuttoned, thick jewellery across their chests, a gun in each hand.

I sat down in Miriam's sitting room, facing the open door, my shoes resting on the linoleum floor that kept out the fine beach sand that covers the Cape Flats: an impoverished peri-urban area with an HIV prevalence of 33% (NDOH, 2011), that stretches across the barren land between the Cape Peninsula's two oceans. A translucent line had been walked into the linoleum; like a thin membrane it linked the kitchen to the bedroom and broadened out around the single-seat couch that Miriam sat on when she made her bowls - bowls then sold to a local organisation that, in Miriam's words, "exploited my HIV". A sentiment confirmed by the programme manager's description of the five-fold profit margin derived from international sales to boutiques wanting to 'do good' for the 'poor women' whose names were cynically scrawled underneath their bowls and whose stories were told in a glossy brochure attached to the price-tag. The mantelpiece across from the couch displayed photographs of her two children and a single photograph of Miriam, at seventeen, as she stood in front of her high school. She had excelled at the top of her class but was forced to leave three months before her final examinations in order to take care of her mother who had been poisoned through witchcraft. In the course of my fieldwork I came to understand the force of this photograph and the significance of its placement on the mantelpiece opposite the couch where Miriam made her bowls: the photograph bears witness to Miriam beyond labels like HIV-positive, poor, woman. It speaks to the possibility of another life.

In the adjacent bedroom, next to the hand-held mirror on her dressing table, were a cluster of white tubs. Each tub held one third of a triple combination of antiretroviral therapy (ART): 3TC, tenofvir, and aluvia. Despite fighting as an activist to access the life-giving capacity held in the large, hard-to-swallow tablets, Miriam's relationship with antiretrovirals (ARVs) is also one of deep frustration. At times she has said, "My treatment is killing me," referring to aluvia's side effects. By 2011 she was on the third antiretroviral combination and on the second line of treatment along with her twelve-year-old daughter, Nena. Nena started life on the brink of death, compelling Miriam to move to Cape Town in search of health care that could decipher and heal her dying child's body. Through this move, and in the face of the government's obdurate AIDS denialism,

Miriam entered the Médecins Sans Frontières (MSF) trial in 2001. She is one of the first people to start ARVs in South Africa's public sector.

Months later, after spending the morning in a clinic with the women I worked with (who handcrafted bowls with Miriam) as they waited for their monthly supply of ARVs, I went to a workshop with MSF on South Africa's patent laws. The meeting was held in a high-security complex in Obs, a former 'whites-only' area with houses built from bricks, resting on foundations sunk into fertile earth. Obs is spatially buffered by the M5 highway from the violent poverty in the former 'non-white' areas of the Cape Flats. My phone rang as I left MSF's offices. It was Miriam. She wanted to know if I had taken her question to MSF in asking whether there were options for third-line ARVs when she developed resistance to second-line treatment. Looking out from Table Mountain towards Miriam's home, I told her that as far as I understood, third line treatment had been developed, was effective, and was available in the world. But not in South Africa's public sector. We both knew what lay beneath my words: that for Miriam – when labels like HIV-positive, poor, woman become salient – her life would end when her HI virus had mutated sufficiently to outwit her second line medicines; medicines held in tubs on her dressing table, provided by the state through her clinic, embodied as she moved through Nkanini's maze of homes into her own. Just as the photograph opposite Miriam's couch spoke to a dissonance in her lived and dreamt reality, the unspoken words between us spoke to the dream of a longer life and the contingent reality of the global governance of the medicines that Miriam embodied.

This thesis centres on the lives of women who, like Miriam, live in Khayelitsha and who receive ARVs through South Africa's public health system. It is tiered across five ethnographic chapters to elucidate a single overarching argument: biopolitical precarity is networked into the permeable body. This argument is based on ethnographic research and seeks to challenge the discursive construction of distance that divorces women's lives and bodies from the governance of life-giving biomedical technologies like ARVs. The multi-sited ethnography underpinning this thesis was configured to follow the networked threads that weave women's embodied precarity into the governance of technologies and the technologies of governance. To this end, fieldwork was conducted in South Africa from October 2010 – July 2011 in order to understand the embodied

and political dimensions of access to AIDS biomedicine.³ Thereafter, fieldwork was conducted in Brazil from August 2011 – September 2011 to explore the networked connections spanning activist organisations, government coalitions and economic blocs to move out from the intimate spaces of women’s lives and bodies to locate them in the regional and global spaces of technological developments and health policy dynamics.

As a challenge to the hegemonic positioning of women as victims, particularly within development discourse, this thesis explores the strategic performance of precarity by women as they negotiate complex assemblages of affective relationships, government institutions and global coalitions to secure their vitality. In sum, this thesis traces the networked threads linking funders in boardrooms in New York to EU-India trade negotiations and protests in Delhi to activists in Recife and Khayelitsha, along Nkanini’s dusty streets, through battered doors of corrugated-iron homes into plastic tubs holding medical technologies that enable life and, ultimately, into women’s bodies and activisms that transform these technologies just as they are transformed by them.

1.1. Research Focus

Medicine and its techniques ask questions of life (Marsland, 2012: 463).

[T]he human body in health and illness is not an ontological given but a moveable, malleable entity – the elusive product of nature and culture that refuses to be pinned down. Without attention to this malleability and to the social and political context in which people live out their lives, technological interventions will often result in unintended consequences and will exacerbate rather than heal global inequities and health disparities (Lock and Nguyen, 2010: 14).

Highly Active Antiretroviral Therapy (HAART), a cocktail of at least three ARVs, was introduced in 1996 as a technological intervention with the capacity to transform HIV from an acute illness and

³ I use the term ‘AIDS biomedicine’ with a practical and theoretical denotation. Practically, AIDS biomedicine denotes the range of allopathic biomedical interventions developed for people living with HIV. AIDS biomedicine specifically refers to highly active antiretroviral therapy (HAART): a combination of ARVs that prohibit the replication of HI virus and stem the proliferation of opportunistic infections associated with AIDS. On a theoretical level, I use the term AIDS biomedicine to indicate the approach I take to biomedicine as a technology and to connect this thesis to specific sets of literature in medical anthropology and science studies that engage with medicine as a material-semiotic hybrid that is governed and embodied in particular ways; this is discussed in the theoretical framework.

precursor of death to a chronic and manageable health condition. When starting my fieldwork, I aimed to understand the political and embodied dimensions of access to ARVs, as a technological intervention, in HIV-positive women's lives. Through my fieldwork, however, it became clear that although it is crucial to anchor technologies in people's lives, it is also analytically and politically necessary to link people's lives - and the technologies that sustain them - back into the global assemblage that is networked around the governance of these technologies. I therefore draw on Lock and Nguyen's (2010) injunction above to locate biomedical technologies in social and political contexts. However, I propose through this thesis that people's lives need to be understood as part of a complex network of actors (spanning international organisations, regional coalitions and national governments) and actants (HIV and ARVs) that assemble in dynamic configurations and are woven into and through the body.

The multi-sited ethnography underpinning this thesis was therefore configured to explore and link the political and embodied dimensions of accessing AIDS biomedicine as a life-sustaining technological intervention. As such, it asked:

1. How are AIDS biomedicines perceived and embodied by women?
2. How do women engage with the state and practise citizenship around AIDS biomedicines?

These questions guided the conceptual and methodological framework, and the structure of this thesis. Therefore, when I refer to the 'embodied' and 'political' dimensions of my research, I denote the composite nature of each question with the related fieldwork and research findings.

The embodied and political research dimensions were informed by my research background and by the shifts in South Africa's biomedical and political landscape between 2000 and 2010. The research dimensions, in turn, informed the methodology, are reflected in the findings, and explored iteratively over five ethnographic chapters. While these two dimensions form the foundation of my thesis, the argument I develop across the chapters – that biopolitical precarity is networked into the permeable body – emerges at their intersection.

1.2. Research Background

1.2.1. From the Inside Out: A Personal History

This thesis builds on my personal and professional history as a South African, as a researcher and as an activist. In 2003, I conducted ethnographic research with a home-based care organisation on the ramifications of the post-Apartheid government's decentralisation of health care for people living with HIV, and on women who provided home-based care to them. The implications of poverty, gender inequality and crumbling public health systems were borne as young men and women died in their homes, frequently under the care of mothers and grandmothers, without access to ARVs and often without any food. Just as I was completing my fieldwork that year, cabinet instructed the government to initiate a 'universal' ARV roll-out following years of high-level political equivocation on the efficacy of AIDS biomedicine. In 2004, the government commenced the universal roll-out, but leaders like Health Minister Manto Tshabalala-Msimang continued to dispute the efficacy of ARVs compared to alternative approaches, including traditional medicine and nutritional supplements (Ashforth and Nattrass, 2006; Nattrass, 2007). During this period of contestation over the efficacy or toxicity of AIDS biomedicine, South African activists and researchers turned to other middle-income countries with high levels of inequality, like Brazil, to highlight the positive potential that ARVs held for transforming HIV into a chronic and manageable illness.



Figure 1.1. *Tshabalala-Msimang returns to work, Zapiro Cartoon, 24/05/2007 (Source: Africacrisis.org, 2007).*

In 2007, I worked with Nozizwe Madlala-Routledge, the Former Deputy Minister of Health, to support her in developing of the 2007 – 2011 HIV/AIDS and STIs National Strategic Plan. A period of unprecedented collaboration between HIV activists, policy makers and civil society blossomed under Madlala-Routledge's leadership (in the absence of the Health Minister, who was incapacitated in hospital). Still, six months later, Madlala-Routledge was

fired by then-President Mbeki, and Tshabalala-Msimang resumed her position in office.

Confounded by these actions I, too, looked to Brazil to understand how the government had addressed HIV in the early 1990s. Over time, however, I came to see the grey – the uncertainty, hope and risk linked to illness and to treatment – that lay between the black of ‘AIDS denial’ and white of ‘AIDS science’. I also came to see how South African academics and activists, like myself, had constructed a narrative of Brazil as the ‘activist state’ in contrast to South Africa as the ‘denialist state’; in both contexts, access to biomedicine was framed by activists as access to life, and linked into assumptions of the democratic state’s responsibility to ensure the lives of its citizens through public provision of AIDS biomedicine.

In 2008 I collaborated with researchers at the Federal University of Pernambuco (UFPE) in Recife, Brazil, where my colleagues highlighted some of the shortfalls of their country’s HIV response, particularly in light of the increased rates of infection among poor women in the North East of Brazil. In conjunction with my research in South Africa, and collaboration with HIV researchers in Brazil, I came to understand some of these narratives more critically, to see that they were useful for particular political and activist purposes, but that they were also fraught with complexity that elides easy categorisation and discursive polarisation. The muddiness intrigued me. Not only did I start to understand Brazil’s history of AIDS activism more critically, but through my research I came to appreciate that South Africa’s struggle for ARVs was far more nuanced than the black and white debate around AIDS ‘science’ and ‘denialism’ (Mills, 2005, 2006, 2008). I saw as my friends struggled with serious side effects, and rather than talking to people in their treatment support group or to their doctors (because they were afraid of being ‘outed’ as denialists), they stopped their treatment altogether. I saw how government officials, like the Deputy Health Minister, worked to transform South Africa’s AIDS treatment policies (among other HIV-related policies) at the risk of their political career. People who found themselves in these grey spaces seemed to be ‘disciplined’ on both sides of the ‘activist/state’ continuum. A parallel process occurred: Brazil’s ‘activist state’ mythology was debunked, for me, through my collaboration with UFPE; and I began to question the way the ‘activist/state’ dichotomy was used (and useful) in South Africa.

My PhD research proposal was an outcome of these ontological and epistemological journeys. I became far more interested in how people themselves thought about the science of medicine as they experienced ARVs in their body; and I was intrigued to understand more about the

relationship between people's embodied experiences of illness (with HIV) and health (on ARVs) and their perception of the post-apartheid government as it was, at that time, just over a decade old.

Again, ethnography turned this thinking inside out. I found that illness is held in memories, bodies and relationships, and that it is not simply about the presence of a virus. I learnt that health is not only enabled through ARVs but that these technologies can also engender other kinds of embodied struggles, and that the virus, too, can enable different kinds of wellbeing. Finally, I saw how politics permeates every facet of our being, and that we too often do not – or cannot – hold actors in this global assemblage to account for the way they intimately affect our lives from a distance, at the most molecular level.

1.2.2. From the Outside In: A Political History

The journey of HIV and ARVs over South Africa's borders and into people's lives and bodies is told through many different kinds of stories. This thesis speaks to South Africa's history through ethnography, and specifically through anamnesis (defined in the thesis as the dynamic recollection and embodiment of illness) as the memory of this history was held in people's bodies and borne through their relationships. Whilst this thesis is based on ethnography, I relay and quantify this history with statistics here as they most concisely convey the context of my research in South Africa and more briefly in Brazil.

In South Africa's total population of 51.2 million people, an estimated 5.6 million were living with HIV in 2012 (UNAIDS, 2012).⁴ Looking to the other edge of the epidemic thirty years ago: HIV was first recorded in South Africa in 1982 when two homosexual men were diagnosed with the virus. This discovery was followed by a study among homosexual men in Johannesburg, South Africa's largest city, where 12.8% were HIV-positive (Sher, 1989). By 1991, cases of heterosexual and homosexual HIV transmission were equal and since then, heterosexual transmission has become the main route through which HIV has moved into the general population (Whiteside and Sunter, 2000).

⁴ <http://data.worldbank.org/country/south-africa>; accessed August 2013.

South Africa's HIV prevalence stands at 17.3% (UNAIDS, 2012). Looking more closely into South Africa, these figures vary substantially across different parts of the country, and among different population groups. For example, the province of Kwa-Zulu Natal has the highest HIV prevalence (37.4%) among 15 – 49 year olds, whereas the province in which I conducted my fieldwork, the Western Cape, has one of the lowest prevalence levels (18.2%) among this same population group (NDOH, 2011). Of the six local government districts in the Western Cape Province, the area in which I worked – the Cape Metropole – had a prevalence of 19.8% in 2011; zooming into Khayelitsha, almost one third of its residents live with HIV as it has an estimated prevalence of 33.1% (NDOH, 2011). I discuss these data in detail in the methodology chapter, but wish to note here that the majority of the people with whom I worked travelled from the adjacent Eastern Cape Province to access health care, education and employment in the Western Cape; prevalence in the Eastern Cape is significantly higher than in the Western Cape. The map below, developed by the National Department of Health (NDOH), provides an overview of the distribution of HIV across South Africa.

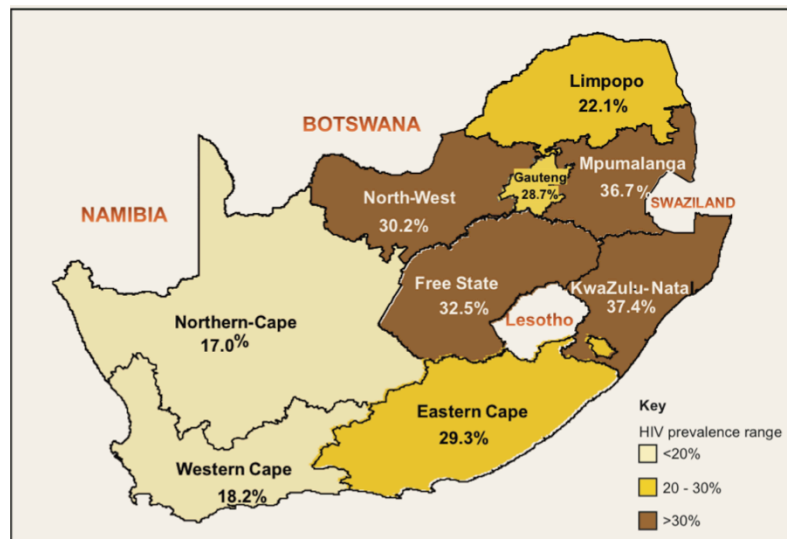


Figure 1.2. Map of HIV prevalence in each province of South Africa (Source: NDOH, 2011)

HIV prevalence in South Africa also varies significantly across age and sex. With a prevalence of 11.9%, women aged 15 – 24 years are almost twice as likely to be HIV-positive than men of this same age group (5.3%) (Dorrington, Johnson, Bradshaw and Daniel, 2006). In 2011, the group with highest prevalence (42.2%) in the country lies with the age group of women with whom I worked (aged 30 – 34). In this same year, South Africa reported 270, 190 AIDS-related deaths; a decade earlier, in 2001, almost 100, 000 more people died of AIDS-related causes (UNAIDS, 2012). A study

published in 2013 confirmed, for the first time in South Africa's history, that people starting on ARV therapy (with a CD4 count above 200 cells/mm) can expect a near-normal life expectancy (Johnson, Mossong, Dorrington, Schomaker, Hoffmann, Keiser, Fox, Wood, Prozesky and Giddy, 2013).

The shifts in the HIV epidemic and in the vitality of South Africans tessellate with policy shifts in the provision of ARVs. It is predominantly in this space – where life expectancy and ARV provision intersect – that comparisons between South Africa's delayed roll-out and Brazil's advanced roll-out are made (TAC, 2010; Nunn, Dickman, Nattrass, Cornwall and Gruskin, 2012). Nunn, whose work traces the evolution of Brazil's treatment policies, encapsulates the comparison here, saying: "Brazil's story contrasts starkly with that of South Africa, which had similar HIV prevalence in 1990 but only began providing treatment on a large scale in recent years and now has the most HIV/AIDS cases of any country." (Nunn, da Fonseca, Bastos and Gruskin, 2009: 1104). In 1997, just as HAART became internationally available, Brazil was the first developing country to commit to providing AIDS treatment to its citizens (Teixeira, 2003; Biehl, 2004, 2005; Okie, 2006a; Cataldo, 2008; Mauchline, 2008). At that time, Brazil had the second highest number of reported HIV cases in the world (after the United States) (Brasil, 1988) compared to South Africa, which had an HIV prevalence of just under 1%. Now, Brazil's prevalence remains below 1% and South Africa is home to the largest number of people living with HIV in any one country in the world (UNAIDS, 2012). The reasons for these very different epidemiological profiles are well documented, and reference Brazil's proactive stance on HIV prevention and its provision of AIDS therapies to its citizens that (largely) corresponded with the pace at which they were developed and released internationally (Galvao, 2005; Okie, 2006a; Cataldo, 2008; Nunn *et al.*, 2009; Brazil, 2012). In 2004 the World Bank reported that Brazil's AIDS response had averted more than half the 1.2 million projected AIDS cases (from 1990) (Biehl, 2007). By contrast, it was only in 2004 that ARVs first started to trickle into South Africa's public sector.

The graph below indicates the scale of mortality among women in South Africa between 1997 and 2004, in comparison with Brazil in 2004⁵:

⁵ <http://www.tac.org.za/community/node/2182>. Retrieved April 2008. This graph draws on mortality data from Statistics South Africa and Instituto Brasileiro de Geografia e Estatística.

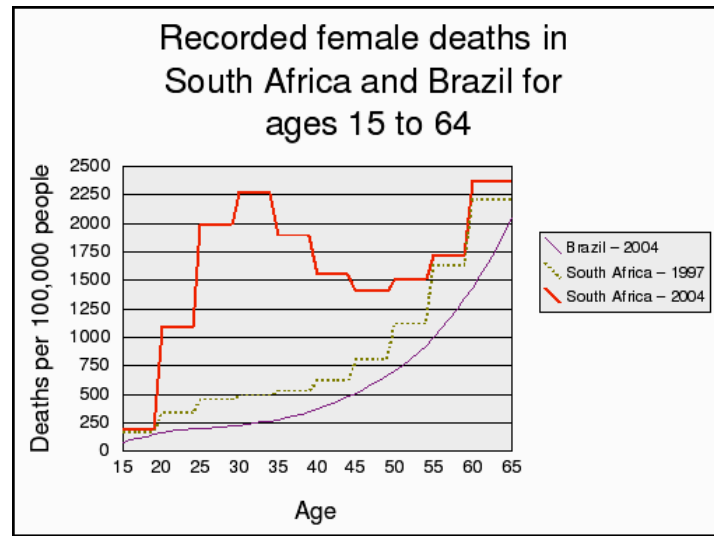


Figure 1.3. Graph of mortality according to sex and age in Brazil and South Africa (Source: TAC/MSF, 2004)

These figures become more textured when held up next to South Africa's political leadership, as ideological battles around the science of medicine, mortality rates and life expectancy shaped the stuttered start of what has eventually become the world's largest ARV program.



Figure 1.4. What AIDS crisis? Zapiro Cartoon, 11/02/2004 (Source: The Sowetan Newspaper, 2004)

During President Mbeki's tenure, South Africa witnessed a sharp decline in life expectancy as people died of AIDS when they could have lived with HIV on treatment. Death notification data (on which the above graph is based) from 1997 – 2004 show that the rate of death among women aged 25 – 54 more than quadrupled, and that it more than doubled among men aged 30 – 39 (Dorrington *et al.*,

2006; Johnson *et al.*, 2013). In 2008, researchers found that a third of a million people died as a result of the Mbeki-administration's AIDS policies between 2000 and 2005 (Chigwedere, Seage, Gruskin, Lee and Essex, 2008). The ASSA2008 model calculated that, with the ARV roll-out from 2004, there had been a significant decline the number of AIDS-related deaths, from 257, 000 in 2005, to 194, 000 in 2010 (Johnson, 2012)

Under the new leadership of President Zuma and Health Minister Aaron Motsoaledi, treatment services were scaled up by 75% between 2009 and 2011, when I completed my fieldwork. By October 2012, 80% of all people in need of ARVs – approximately 2 million people – received ARVs through the public health system (UNAIDS, 2012). With the highest number of people living with HIV, and on ARVs, South Africa now has the largest ARV programme in the world. Numerous actors, spanning local, national and transnational activist networks, national leaders, evolving intellectual property agreements and international biomedical research developments, have all played a role in moving ARVs into South Africa's public health system, and into people's bodies and lives. I discuss the role of these actors below.

I did not set out to conduct a comparative analysis of HIV-positive people's mobilisation for ARVs in Brazil and South Africa; however, for the political and ethical reasons I discuss above, I did want to locate my ethnography in a global topography. Therefore, as I discuss in the methodology below, I conducted fieldwork in South Africa for ten months and in Brazil for two months. The balance of my research in South Africa (80%) and Brazil (20%) is reflected in the weight of my five ethnographic chapters, and in the structure of the argument I develop across my thesis: the first four ethnographic chapters are located in South Africa, and they move out in scale from under the skin into women's social relationships and their political engagement with the state. The fifth ethnographic chapter looks between South Africa and Brazil, and traces the networks that link these countries to India, its pharmaceutical industry and its relationship with the European Union. Finally, the thesis circles back to look at how the women I worked with in Khayelitsha are networked into this global assemblage.

1.3. Research Rationale

Jasanoff (2005) refers to two destabilising changes in the ways that we understand and view the world. First, a cognitive shift from a realist to constructivist understanding of science and knowledge has opened up space for scepticism around absolutist claims, and awareness of risks, uncertainty and safety. Second, the fragmented authority of the state has prompted a political shift, and has generated a rethinking of democratic governance and the state's ability to discern and meet citizens' needs (Jasanoff, 2005).

The rationale underpinning the embodied facet of my research connects with the first shift away from absolute claims to certainty, and towards a recognition of complexity as I sought to understand how women embody and experience AIDS biomedicine beyond the black and white discourse of ‘the politics of life’ that unambiguously positions biomedical technologies as a ‘fix’ to the problem of HIV. I do not dispute whether or not ARVs extend lives. Rather, I was interested to understand how women embody medicine in their lives and how these medicines may hold hope alongside uncertainty beyond AIDS activist discourses that cast these technologies as unequivocally ‘life-giving’. The first component of the rationale, therefore, connects to the first dimension of my research focus. Similarly, it informed my methodology and connects with final part of my conceptual framework in which I explore theories of embodiment, performativity and precarity.

The second part of my rationale connects to and builds on the political shift identified by Jasanoff (2005), as it relates to the second dimension of my research focus. Through this facet of my research I sought to understand how the South African state was imagined by citizens in relation to the set of needs they identified when ‘seeing’ and ‘speaking’ to the state. I also aimed to explore how HIV-positive citizens act on the state (and are not simply acted on) within a broader network of actors that spans local, national, regional and global sites of engagement around AIDS biomedicine. Like the first component of my rationale, it also informed my research methodology (as I go on to discuss) and connects with the conceptual framework in which I explore theories of biopolitics, biosociality, imaginaries of the state and everyday forms of citizenship.

I locate these two components of my rationale in the shifting biomedical and political landscape of South Africa, and focus in particular on the decade leading up to my fieldwork, from 2000 – 2010. I cannot, given the scope of this thesis, enter into a detailed review here of South Africa’s history, particularly of Apartheid; I therefore enter into slightly more detail of this longer-term history where it is relevant in the ethnographic chapters.

1.3.1. A Shifting Biomedical Landscape

The rationale underpinning the first facet – the embodied dimension of AIDS biomedicine – centres on the construction of AIDS biomedicine as a solution to HIV, or as biomedicine has more

recently been described, as a ‘technofix’ to illness: a magic bullet that catalyses a linear transition from ‘near death’ to ‘full life’ (Lock and Nguyen, 2010). Jasanoff’s (2005) account of the cognitive shift in approaches to scientific knowledge (away from assertions of certainty and towards a recognition of ambiguity), relates to my aim to understand how HIV and ARVs were thought about, talked about, and embodied in people’s everyday lives.

Lock and Nguyen (2010) suggest that two assumptions underline the premise that AIDS biomedicine is a magic bullet for restoring health and sustaining life. First, the assumption that biomedical technologies are autonomous entities reinforces the construction of health-related matters as objective, quantifiable and technically manageable: but “biomedical technologies are not autonomous entities: their development and implementation are enmeshed with medical, social, and political interests that have practical and moral consequences” (2010: 1).

Drawing on Appadurai’s (1988) concept of the ‘social lives of things’, medicines can perhaps more accurately be understood as ‘things’, or material medica, that have social lives (Whyte, van der Geest and Hardon, 2002). These two distinct but related approaches to ‘things’ and to ‘materia medica’ bear relevance in slightly different ways to this strand of the rationale. Appadurai (1988) suggests that in following the circulation of commodities, we not only look at the function they perform in exchange (see Mauss, 2002) but at the value they embody. Simmel (1978), he writes, proposed that value is not inherent to objects, but rather something that we ascribe to them through exchanges of sacrifice. However, Appadurai (1988) uses Simmel’s (1978) observation to think about the way that “economic objects circulate in different regimes of value in space and time”, reflecting on the edited collection of essays that offer “glimpses of the ways in which desire and demand, reciprocal sacrifice and power interact to create economic value in specific social situations” (1988: 4).

When ARVs first became available to the international market, in 1996, only a very small minority of wealthy people were able to afford these medicines (Epstein, 1996). With this in mind, Appadurai (1988) prompts us to think that the value of these ‘things’ do not only lie in the prices that countries and people pay pharmaceutical companies in exchange for them, but also in the way their value is conceptualised and negotiated. The idea of the social lives of things is useful to trace the biographies of medicines and the complex political and economic negotiations that have

brought them into countries like South Africa, and into the lives of the people I worked with in Khayelitsha. However, their significance extends beyond their economic value established through systems of exchange: it includes the value medicines take on, in people's bodies and lives. In this respect, Whyte, van der Geest and Hardon's (2002) approach to the social uses and consequences of medicines, as the material 'things' of therapy, offered a more honed set of tools for anthropologists to work with when thinking about biomedicine. While recognising that medicines take many different forms, they focussed – as I do – on commercially manufactured synthetic medicines produced by the pharmaceutical industry. They recognise that biomedicines are commodities with a social life. "They have vigorous commodity careers; their dissemination to every part of the global has far-reaching implications for local medical systems" (Whyte *et al.*, 2002: 3). But beyond their commodity value and the notion that these 'things' have histories that shape their current form, Whyte *et al.* also emphasise the extent to which medicines "are the most personal of material objects" (2002: 3), threaded through the very fabric of social relationships.

The second assumption that Lock and Nguyen (2010) critique, and that informs the second strand of this rationale for my research, relates to the positivist construction of bodies as being essentially the same. Not only were biomedicines left largely unexamined, a "gold standard against which other theories of bodily affliction could be measured" (Brotherton and Nguyen, 2013a: 287) but bodies were 'black-boxed', left by anthropologists to be probed by biologists. This was, for laudable reasons, due to the scientific racism of the nineteenth and twentieth centuries that equated race with biological difference and discursively located this difference in the body (Lock and Nguyen, 2010; Lock, 2012; Bharadwaj, 2013). The cost is that, "[W]e are now blind to how social and political processes produce biological difference, and by extension, how biomedical interventions may unwittingly perpetuate or enact further inequalities" (Brotherton and Nguyen, 2013a: 288). Thus, not only are medical technologies dynamic as explored above, but that they interact differently with different kinds of bodies.

Assertions of bodily sameness, among AIDS activists in South Africa (Robins and Von Lieres, 2004) and Burkina Faso (Nguyen, 2005) for example, may account for successful collective action that cohered around HIV as a shared illness predicament. However, while assertions by these collectives, also described as therapeutic citizens (Nguyen, 2005), have certainly been powerful in

the history of AIDS activism (as I discuss in the following section), they have not accounted for the dynamic pathways that connect mutating viruses with ARVs in unique bodies that are located in shifting social, economic and political environments. For, we see that combinations of AIDS biomedicine and regulations for the commencement of treatment are regularly revised by the World Health Organisation (WHO) and by national governments.⁶ South Africa, for example, has recently amended its treatment guidelines, and has stipulated the withdrawal of stavudine (d4T) from first line treatment regimens because of the high levels of reported side effects, including peripheral neuropathy, lactic acidosis and lipodystrophy.⁷ Acknowledging uncertainty linked to the non-uniform effects of AIDS biomedicine and recognising bodily difference pose challenges to activist discourse that mobilises around certain benefits of HAART in addressing the shared vulnerability of HIV-positive people as a collective group.

With this in mind, I sought to understand the dynamic interactions between individual bodies and complex biomedical technologies beyond the assumption that ARVs precipitate a transition from bare life to full health. As such, the first dimension of my research sought to explore these embodied dimensions and asked: how are AIDS biomedicines perceived and embodied by women?

1.3.2. A Shifting Political Landscape

This section relates to the second dimension of my research rationale and situates the emergence of HIV and the provision of ARVs in South Africa's political landscape. In line with the second shift that Jasanoff (2005) identifies, it draws in a set of local, national and transnational actors and illustrates the porosity of South Africa's government and the constraints (and failures) entailed in its ability to respond to its citizens' needs for life-saving AIDS therapies. This relates to the second research question, which asked: how do women engage with the state and practise citizenship around AIDS biomedicines?

HIV started to move into South Africa's general population just as the country was moving towards democracy. During this final decade of apartheid, the government declared two states of

⁶ In 2007 the WHO set up a pharmacovigilance programme to monitor national reports of HAART side-effects, and have also recently revised recommended doses of Stavudine in order to reduce risks of associated side-effects. <http://www.aidsmap.com/en/news/B153727A-1CDC-44E9-AC17-6E46BA2F771D.asp>; accessed June 2012.

⁷ http://www.aidsinfonet.org/fact_sheets/view/414; accessed June 2012.

emergency (in 1985 and 1988) that amplified violence across South Africa: by the time Nelson Mandela was released in 1990 the focus was necessarily on enabling a peaceful transition. Still, 1990 marks the country's first coherent response to the HIV epidemic: the African National Congress (ANC), along with other anti-apartheid activists and regional government officials attended the Fourth International Conference on Health in South Africa and released the Maputo Statement on HIV and AIDS calling on leaders to address the HIV epidemic, and to focus on prevention and the rights of HIV-positive people (Heywood and Cornell, 1998). It was at this meeting that Chris Hani, the head of uMkhonto We Sizwe (the ANC's armed wing), said: "We cannot afford to allow the AIDS epidemic to ruin the realization of our dreams" (Itano, 2007: 144). In 1992, a broad coalition of actors from civic groups, trade unions, business organisations, political parties and academics formed the National AIDS Coordinating Committee of South Africa (NACOSA); it is largely due to NACOSA's AIDS strategy that the ANC government was able to adopt a National AIDS Plan within months of the first democratic election in 1994 (Heywood and Cornell, 1998).

However, one of the first signs that HIV was not a priority for the Mandela-administration was the appointment of the AIDS Programme Director to the Department of Health and not to the President's Office, as originally stipulated in the National AIDS Plan. Other factors accounting for the delayed response to HIV during President Mandela's tenure include: bureaucratic restructuring; the devolution of authority to provincial governments; the absence of a coherent strategy for addressing HIV as a multi-faceted human rights issue rather than a specific health concern (Crewe, 2000). These factors were later disputed by critics who argued that, "There is a limit to how long a government can blame its own bureaucracy without being held to account for that failure" (Nattrass, 2004: 44).

Whilst the first term of democratic governance (1994 – 1999) under the Mandela-administration can be described as one of political inaction with respect to HIV, the subsequent two terms (1999 – 2008) under the Mbeki-administration, are more aptly described as periods of political negligence.

For almost a decade (1999 – 2008), the South African government under the leadership of President Thabo Mbeki and his Health Ministers prevaricated on the public provision of ARVs.

Initially, the government claimed that it was simply too expensive to provide these essential biomedicines. This economic logic was quickly dismantled, as the government was shown that it would be substantially more expensive to not provide ARVs (Nattrass, 2004). When President Mbeki, elected in 1999, convened an AIDS Advisory Panel and consulted with AIDS denialists like Peter Duesberg, it became apparent that his objection was not on economic grounds, but on ideological ones (Geffen, 2005).⁸ For, even in 2001 when the government, along with the Treatment Action Campaign (TAC), protected a law to allow for the domestic production of generic brand medicines, it still did not start to provide ARVs to the hundreds of thousands of people who were dying prematurely of AIDS (TAC, 2010).

South Africa's particular history challenges the view that scientific knowledge is a straightforward matter of 'rationality' and a condition of 'democratic emancipation' as Geffen (2010) and Nattrass (2008, 2012) assert. Instead, I suggest that equivocation around the science of HIV and of AIDS biomedicines may also relate to a complex political history that calls into focus epistemological questions around the deficit model of science (Leach, 2005). For instance, some biomedicines, like depo provera (an injection contraceptive), were used by the apartheid government to control Black men and women's bodies and their sexual reproduction (Brown, 1987).⁹ Looking from biomedicines to viruses, we see, too, that beliefs that white people introduced HIV as a means to control the Black population echo the documented actions of apartheid's Defence Force and employees, like Wouter Basson who researched the use of HIV in biological warfare (Fassin and Schneider, 2003; Youde, 2005).

Mbeki's pseudoscientific approach to the science of HIV perhaps emerges, in part, from this complex history as he sought to destabilise the epidemiological link between unprotected sex and HIV transmission by foregrounding poverty as the primary structural determinant of HIV infection (Nattrass, 2008). By tethering HIV prevalence to structural inequality, Mbeki aimed to challenge racist assumptions that Black people were more likely to be HIV-positive because they were more sexually voracious than other race groups (Gevisser, 2008). (These were the same kind of racist and pseudoscientific assumptions, discussed above, that medical anthropologists backed away

⁸ Professor of molecular and cell biology at the University of California, Berkley, he claims that HIV does not cause AIDS.

⁹ The use of racial terms is problematic as it assigns essentialist categories of difference to people based on their skin colour; in South Africa, these categorisations have been used to exert social, economic and political power in deeply oppressive regimes. I therefore use the capitalised term 'Black', in line with the Black Consciousness Movement's (BCM), to indicate my awareness of the political dimension of race in South Africa, and to denote (as the BCM does) the range of 'racial groups' that were systematically marginalised through pseudo-scientific constructions of racial difference under colonial and apartheid rule.

from when researching the body in the 18th and 19th century). In this way, Mbeki focussed on holding South Africa's colonial and apartheid history accountable for its HIV crisis. In a cruel twist of irony, this meant that his administration did not develop the vital policies that that would ensure, in this postcolonial era, that the lives of South African citizens were secured through the timely provision of AIDS treatment. As Comaroff wryly observes, "[W]hile his regime is admirably postcolonial in many respects, Thabo Mbeki's stance on AIDS speaks less to a new mode of sovereignty than to the continuing impact of colonial ideologies that have tied life even at its most bioscientific, to racialised sexuality" (2007: 214).

Mbeki's epistemological equivocation had material implications for the vitality and mortality of HIV-positive South Africans who were, as a result of his administration's political negligence, unable to access life-saving AIDS biomedicines through the public health sector. Over 340, 000 lives were lost under President Mbeki's term in office as a result of his government's failure to scale up the provision of ARVs (Chigwedere *et al.*, 2008; Nattrass, 2008).

The emergence and large-scale political mobilisation of the Treatment Action Campaign in the period of Mbeki-administration perhaps best illustrates the transection between the local and the global in South Africa's shifting political landscape. I trace this account here as my fieldwork took place with a group of people who had worked with TAC at the height of the struggle for AIDS biomedicines. It is important to note, too, that while I worked with TAC and with many people who had been AIDS activists, my fieldwork found that these political landscapes continued shifting and new kinds of biopolitical struggles, including but stretching beyond biomedicine, were emerging in people's everyday lives, relationships and citizenships.

There were five main strategies through which TAC worked across transnational geographies and political ideologies, to:

[R]econnect bioscience to a critical, redemptive sociology, dedicating itself to mass education about the social etiology of the disease, about drugs and the political economy of their global distribution, about the constitutional entitlement of ordinary citizens to health. In short, to a politics that links a not-so-bare life to a more robust practice of citizenship (Comaroff, 2007: 214).

First, TAC built a cadre of activists. This was done in part by harnessing the science of HIV and AIDS treatment through their Treatment Literacy Program (TLP). Through this programme, ‘scientifically literate’ activists were – irrespective of their formal education levels – able to use the language and logic of biomedical science to highlight the importance of making ARVs available to South Africans (Robins, 2006). The large numbers of people who cohered in biosocial groups (Rabinow, 1996) around the struggle for ARVs, through marches for example, made this particular kind of biopolitics visible to the government and the world, as they brought their bodies into public spaces to bear witness to their embodied vulnerability without access to ARVs. TAC’s first public event set the stage for foregrounding the relationship between citizens’ vitality and access to medicines: it held a Fast to Save Lives on 21 March 1999 at the Chris Hani Baragwanath Hospital in Soweto, Johannesburg (TAC, 2010). The images from this event flew across South Africa’s television screens, as the country witnessed images reminiscent of the anti-apartheid struggle in post-apartheid South Africa: activists lay on the ground in a ‘die in’ to symbolise their death and to make the connection between AIDS treatment and life visible to a government that was refusing to bear witness to the escalation of AIDS-related mortality (Geffen, 2010). By 2010, when I started fieldwork, TAC had over 10, 000 members, and was active in community-level branches across the country. These community-level branches cohered around six district offices, and cascaded into one national office in Cape Town.

Second, TAC used the law. TAC worked most closely with the AIDS Law Project in Johannesburg (now called Section 27). Jonathan Berger, one of the key actors in this organisation, describes how TAC used the constitution ‘as a tool’:

TAC’s work is deeply grounded in the Constitution – in the rights it recognises, in the obligations it imposes on the state and the private sector, and in its recognition of the importance of the rule of law to good governance, accountability and service delivery. This understanding of the Constitution has helped TAC to frame its demands in human rights language and use the law as a tool for progressive social change (TAC, 2010: 29).

Third, TAC worked with international partners to show the government that ARVs work. This was primarily accomplished through TAC’s partnership with MSF. In 2000 MSF set up three clinics in Khayelitsha to provide ARVs to people who were most urgently in need of treatment to survive. In 2003 TAC and MSF set up a second trial in rural Lusikisiki, in the adjacent Eastern Cape Province. A number of the people I worked with, like Miriam, joined TAC when they started ARVs through the

MSF trial in Khayelitsha. The data from MSF's ARV trial in Khayelitsha offered sufficient evidence for cabinet to order the government to initiate a public sector ARV roll-out in August 2003 (Nattrass, 2012).

Fourth, TAC took to the streets in protest against the government. In 2002, TAC voted to initiate a countrywide civil disobedience campaign, and to increase the use of marches. TAC's civil disobedience campaign, called 'Dying for Treatment', aimed to alert the government and the international community to the mortal implications of the government's failure to deliver a treatment plan. 'Die ins' were one of multiple forms of protest actions (including marches, disruptions to parliament, law suits) and they were used across the world to show the precarious nature of life in South Africa.

Finally, TAC challenged pharmaceutical companies to make AIDS biomedicine more affordable to low and middle-income countries. Initially, TAC joined the South African government in a case that had been brought against it by the Pharmaceutical Manufacturers' Association (PMA) and 40 multinational drug companies. The PMA sought to stop the enactment of the Medicines and Related Control Amendment Act (1997) that allowed for the substitution of brand-name drugs once the patent had expired; the act also allowed for the importation of generic medicines. The PMA were publically denounced by TAC's members who stood outside the court in garish masks that caricatured the PMA as 'fat cat corporates' complicit in the death of South Africans who could not afford their drugs. Shamed by these public actions, and by TAC's activist network that denounced pharmaceutical profiteering in countries like Brazil and Thailand, the PMA dropped the court action in 2001. TAC also challenged specific pharmaceutical companies to make their medicines more affordable by threatening to use this law to import generics (Robins, 2005; TAC, 2010).

The transition to a new South African government in 2009 marked a further shift in the politics of science linked to HIV and AIDS biomedicine; this political shift has also had significant material implications for the lives of HIV-positive South Africans. As described in the background section above, South Africa has scaled up treatment services by 75% between 2009 and 2011 (UNAIDS, 2012), and reached its target of providing ARVs to 80% of all those in need in 2012. It was, historically, this broad-based ARV scale-up that TAC activists lobbied for; essentially, they looked to get medicines into the country rapidly, at affordable prices, and to ensure that they were then

made available to the large number of HIV-positive South Africans in need of this treatment through the public health sector. However, even when the state heeded the activist call to scale up ARVs across the country, there remained (and emerged) a set of challenges that point to the constraints of the government to fully meet the needs of its citizens. These challenges fan out from the historical urgency to make ARVs available to draw in a more complex set of challenges around living with HIV and ARVs in one of the most socio-economically unequal countries in the world. These factors point to the role of the state in sustaining life by providing ARVs, but they also illustrate some of the practical limits of the state's capacity to discern and meet the needs of citizens (Jasanoff, 2005).

Although the South African government scaled up its ART programme, it did so at a lower cluster of differentiation (CD4) threshold (<200 cells/mm³) than advocated by the World Health Organisation (<350 cells/mm³). The government claimed that at that time, in 2010, it could not afford to provide treatment to the higher number of people who would qualify with a higher CD4 count. However, it amended these treatment guidelines in 2011 and now ARVs are initiated at 350 cells/mm³. Despite these policy amendments, their practical realisation is far from optimal and late initiation remains one of the main reasons for what is termed, in biomedical discourse, 'treatment failure'. Treatment failure as a result of late initiation and poor adherence runs alongside multiple emerging concerns that include stock-outs of essential HIV and TB biomedicines in public health centres (Harries, Boxshall, Phiri, van Gorkom, Zachariah, Squire, Makombe, Kwanjana and Gondwe, 2006). As recently as July 2013, ARV stock-outs were reported in three of the eleven provinces in South Africa, as tens of thousands of people were forced to miss doses of their ARVs.¹⁰ TAC and its partners – including MSF and Section 27 – have been organising mass marches and petitions across the country in protest against these emerging struggles.

In addition to the biomedical challenges that are emerging in the wake of the struggle to bring ARVs into South Africa, there remain socio-economic challenges that shape people's everyday lives. Studies have shown that high levels of unemployment and resultant food insecurity affect the wellbeing of individuals and their households (Coetzee and Nattrass, 2004; Hosegood, Preston-Whyte, Busza, Moitse and Timaeus, 2007a), and influence individuals' ability to adhere to their medicines (Le Marcis, 2012). These emergent struggles point to the limits of linking the possibility

¹⁰ <http://www.citypress.co.za/news/clinics-run-out-of-life-saving-arv-drugs/>; accessed September 2013.

of life to availability of AIDS biomedicine. Like my own research that takes place after the height of struggle for AIDS biomedicines, other ethnographic studies on ARV programmes similarly point to the contexts in which ‘lives are lived’ to show that ARVs, alone, are not sufficient for enabling life (Biehl, 2007; Kalofonos, 2008; Marsland, 2012; Marsland and Prince, 2012; Prince, 2012).

The context in which people receive ARVs and are able to ‘live their lives’ is critical, but Miriam’s question about third line ARVs reminds us that HIV-positive people’s embodied vitality is inextricably bound to AIDS biomedicine. South Africa has very recently amended its national ART regimens and finalised a \$US672 million tender to provide newer biomedical technologies in a single Fixed Dose Combination (FDC) tablet.¹¹ This is a significant move towards reducing the difficulties entailed in taking complex regimens of older medicines that generate side effects. However, South Africa’s out-dated intellectual property system lags behind these positive policy developments and is an obstacle to the importation of affordable medicines, particularly third line treatments like raltegravir. In October 2013, for example, TAC issued a statement on its call for legislative reform saying, “[E]vidence highlights how South Africa’s current intellectual property system allows exploitation by foreign companies while impeding the growth of our local industry”.¹²

In this thesis, I refer to the new set of challenges that surface more visibly in the wake of the struggle for AIDS biomedicine as ‘new generation struggles’ and I explore them as they draw attention to the constraints not only placed on the lives of individuals, but also on the governments that are biopolitically implicated in their vitality. These struggles point to the intersection of the shifting biomedical and political landscapes, and together offer scope for considering the biopolitical dimensions in which people’s embodied lives are networked into an assemblage around the politics of life linked to but extending beyond access to AIDS biomedicine. As Comaroff notes,

AIDS has been rewriting the global geopolitical coordinates within which we think and act. We may lack the nerve or imagination to theorise it adequately, but it has certainly been theorizing us for quite a while... The threatening mutability of the disease challenges efforts to impose stable categories of recognition and exclusion in an already disrupted late-modern geography (2007: 198).

¹¹ <http://www.irinnews.org/report/96930/south-africa-new-arv-tender-drops-prices-changes-treatment>; accessed June 2013.

¹² <http://www.fixthepatentlaws.org/?p=710>; accessed October 2013.

In considering these ‘new generation struggles’, this thesis offers a partial response to Comaroff’s challenge as it demonstrates, iteratively across five ethnographic chapters, that these global configurations are networked into an assemblage and embodied in the lives of women like Miriam and the other people with whom I worked.

1.4. Thesis Outline

This thesis traces a network of actants and actors across five ethnographic chapters to illustrate how this assemblage threads biopolitical precarity into women’s lives, and how women act up and through this assemblage to secure their vitality and manage their precarity. I trace the lives of HIV and ARVs as the primary nonhuman actants, in Latour’s terms (2005), across this thesis and explore a set of actors in each chapter that articulate with each other in an assemblage across scale, from under the skin into the national, regional and global arena and back into women’s lives.

Chapter Two details the conceptual framework of the thesis. The first section traces the theoretical trajectory from biopower (Foucault, 2008; Nadesan, 2008) to the politics of life linked to recent technological advances and their implications for governmentality. Thereafter, the chapter critiques this trajectory in light of two sets of literature that engage specifically with the two dimensions of the research focus – the embodiment and politics of AIDS biomedicine. It proposes that actor networks and assemblages might enable an integration of these sets of literature. In conclusion, it introduces the concept of biopolitical precarity to foreground the implications of the assemblage of actors and actants that, this thesis argues, are precariously networked into women’s lives and bodies.

Chapter Three outlines the methodology underpinning this thesis. It outlines how, through ethnographic research in South Africa, I explored the research dimensions discussed in this chapter and the conceptual connections across the two dimensions as discussed in the conceptual framework. It also outlines how, through fieldwork in Brazil, I traced the political threads – linking activist organisations, policy makers and pharmaceutical developments – that I had identified through my fieldwork with multiple actors, across multiples sites, in South Africa.

The subsequent five chapters present the ethnographic findings of my fieldwork. Like Miriam, I asked why she was told to 'be a good girl' and take care of her dying mother at the cost of her education and in Chapter Four (Pathways of Precarity), I discuss how HIV, as an actant, came to enter the bodies and lives of the women I worked with along three pathways. This chapter integrates the concept of biopolitical precarity with epidemiological framings of transmission to understand the social, economic and biopolitical dynamics that enable HIV to move along vertical, horizontal and diagonal pathways into people's bodies.

Chapter Five (New Generation Struggles) introduces ARVs as an actant and explores how both HIV and ARVs, as 'things with social lives', intra-act with each other and with women's bodies. This chapter introduces a set of 'new generation struggles' that generate other further precarious forms of embodiment that move beyond the embodiment of HIV as the 'problem' and ARVs as the 'technofix'. These struggles are related to the shifting biopolitical landscape in South Africa: they include side effects, adherence and viral resistance on ARVs; and relate to the socio-economic conditions in which women 'live their lives' on ARVs in Khayelitsha.

Chapter Six (Embodied Topologies) moves out in scale from the intimate space of women's bodies to situate the body in a network of topologies that join memory and space together through women's recollections of their search for healing at different space-times in South Africa's shifting biopolitical landscape. The first section traces women's illness narratives across salient spaces and times, and along the lineages of social relations that stretch out before and after them. The second section explores women's memories of embodied precarity into the site of Khayelitsha as the space of political resistance in the struggle for democracy and then, later, in the struggle for ARVs.

Moving from considering how space and sociality are embodied and produced through memory, Chapter Seven (Sensate States) considers how shifting socialities intersect with changing citizenship practices as they are embodied, and as they coalesce around emergent biopolitical concerns that fan out from the historic assertion of the right to life linked to AIDS biomedicine in South Africa. It explores multiple dimensions of citizens' imaginaries as they 'saw' and 'spoke' to the state; these imaginaries reflect on and develop the set of 'new generation struggles' that are detailed in the previous chapters and that, I argue, reflect South Africa's shifting biopolitical landscape in the wake of the ARV roll-out.

With the provision of AIDS biomedicine, emergent concerns around access to newer biomedical technologies that have fewer side effects call a set of global actors into focus. These actors include Brazilian activists who have a long history of mobilising the government for access to emerging medical technologies, national governments and countries that produce affordable ARVs (like Brazil and India), regional coalitions (like BRICS) and international actors (like the European Union and World Trade Organisation). Chapter Eight (Therapeutic Governance) explores how these global actors are woven into a network that governs the development and distribution of affordable AIDS medicines, and links the global governance of biomedical technology back into South Africa and its embodied implications for the women with whom I worked whose lives, too, are precariously woven into this network.

Chapter Nine (Biopolitical Precarity) draws the findings of the five ethnographic chapters together, and considers the implications of the shifting biopolitical landscape in which this ethnography was located. In doing so, it explores the limits of agency for both governments and individuals to exert autonomy over their vitality within a global assemblage that draws actants that shape life under the skin (like HIV and ARVs) into a network with actors (like South Africa, India, Brazil, the EU and WTO) that govern the development and distribution of essential AIDS biomedicines. In considering these implications, the conclusion reflects on the value of two overarching contributions of the thesis in researching the intersection between women's embodied experience of biomedicine and their political engagement with the state. First, the concept of diffracted biosocialities reflects the emergence of new generation struggles that fan out from a narrow focus on illness to include and integrate struggles that happen 'inside' the body (linked to HIV and ARVs) with the context 'outside' the body (linked to violence, unemployment, sanitation). Because these emergent struggles are experienced within the body, it is also through the body that they are articulated in people's political dialogues with the state, as activists and as everyday citizens. Second, the related concept of biopolitical precarity shows the entwined relationship between the state of the body and the body of the state, and highlights the value of locating this historic biopolitical relationship in a global terrain in order to hold these multiple actors to account for the extent to which their actions are embodied in women's lives.

1.5. Conclusion

I write this introduction at the conclusion of my PhD journey, cognisant that the starting place for ethnographic research matters:

“If you start from the ‘negative minimalisms’ (Thin 2008: 149) of sheer survival and bare life, of violence, suffering, deprivation, and destitution, then you provide a very different description of lives than if you begin from people’s situated concerns... [O]ur tendency to focus on the dystopic has been at the price of forgetting to think about ‘other ways of thinking’ — supposedly this is what anthropologists do best.” (Marsland, 2012: 464)

This thesis is distinct from the trajectory of these shifting biomedical and political landscapes, and from ethnographies of ARV programmes that were situated in the time lag between the international development of AIDS biomedicines and their provision through national health systems. My research looks at what happens afterwards, when the light turns and the acute and visible struggle for ARVs becomes a chronic and quieter navigation of precarious life.

Situated in a dynamic biopolitical landscape in the decade after ARVs were first introduced, this thesis explores what happens when people’s chronic struggle to survive without ARVs sifts back under the surface and these medicines become ‘embedded’ in their everyday lives, when the possibility of hope attached to these medicines become embodied and then unfolds as a new generation of struggles of risks and side effects. It looks at what happens when the tide of AIDS funding turns, and the global actors articulate a new set of priorities, when national governments start working with, and not against, activist organisations, and when life becomes much more about the struggle against brutal winters as they ease into the bones of people’s bodies in the ‘ephemeral constructions’ (Fassin, 2007) of fragile corrugated iron homes.

Whilst I do not start from a point of ‘negative minimalisms’ that foregrounds the extent to which oppressive structures bear down on people’s ability to navigate their life, this ethnography is also not reflective of the anthropology of hope where, “the fundamental condition of politics is ... plural [and] goes on among plural human beings each of whom can act and start something new” (Marsland and Prince, 2012: 464). This ethnography lies somewhere in the middle: people are its starting place, and because it is situated in their lives, it is a far muddier story. It offers hope in the quieter everyday ways that the people with whom I worked resisted oppressive structures, but it

also asks us to bear witness to the violent politics of their precarious lives under South Africa's bright but also brutal skies.

2. Conceptual Framework

The smallest AIDS virus takes you from sex to the unconscious, then to Africa, tissue cultures, DNA and San Francisco, but the analysts, thinkers, journalists and decision-makers will slice the delicate network traced by the virus for you into tidy compartments where you will find only science, only economy, only social phenomena, only local news, only sentiment, only sex... By all means, they seem to say, let us not mix up knowledge, interest, justice and power. Let us not mix up heaven and earth, the global stage and the local scene, the human and the nonhuman. 'But these imbroglis do the mixing,' you'll say, 'they weave our world together!' 'Act as if they didn't exist,' the analysts reply. They have cut the Gordian knot with a well-honed sword. The shaft is broken: on the left, they have put knowledge of things; on the right, power and human politics (Latour, 1993: 2 - 3).

My ethnography emerged from the intersection of the two dimensions of my research focus; the people I met through my fieldwork took the feminist adage that the personal is political and mixed it up, thoroughly. Women's embodied accounts of the pathways that brought HIV and later ARVs as actants into their bodies implicate a network of actors, including scientists capable of reverse engineering essential AIDS medicines in India's laboratories, South Africa and Brazil's capacity to negotiate international trade law to access these medicines, health systems and its professionals who dispense medicines through small 'ARV-only' pharmaceutical counters in Khayelitsha's clinics, activist coalitions with international organisations like MSF, and fraught relationships that women navigate as individuals, professionals, partners, and parents. I trace the 'social lives' of HIV and ARVs as actants, and explore this set of actors across five ethnographic chapters, each moving out in scale from the molecular to the global arena. I use these scales to organise what is necessarily a structured argument across a linear thesis that moves from one page to another, from one chapter to the next; however, the line of argument is not uni-directional, nor does it fit neatly within a set of theories around structuration and agency (Giddens, 1990) or even practice (Bourdieu, 2001), with governance structures acting down on people's bodies or with people acting up on these structures. Just as my ethnography traced a delicate network that mixed up sex, social phenomena and science, justice and power, the global and local, so too does the conceptual framework outlined below.

The conceptual framework draws together insights from and critical engagements with several literatures to underpin the theoretical and ethical imperative of understanding the embodied ramifications of the governance of AIDS therapies as they are networked through and under the skin of the body – of the individual and of the population. The first section of this chapter outlines how the research draws on the evolution of theory from biopower to the ‘politics of life’ linked to biomedical technology. The second section uses these approaches to engage with medical anthropological theories of the body and embodiment, broadly in relation to the embodied dimension of the research focus and in connection with the first two ethnographic chapters. The third section engages with literature on governance and citizenship, broadly in relation to the political dimension of the research focus, and connects with the final two ethnographic chapters. The fourth section maps out the core concepts that bridge the two dimensions – the embodied and political – of the research focus; these approaches have salience across all chapters, are discussed in particular in the third ethnographic chapter, and include assemblages, actor networks, topologies and anamnesis. The final section outlines the conceptual approach of biopolitical precarity. This section draws the two research facets together, transects the thesis and reflects the overarching argument that biopolitical precarity is networked into the permeable body.

2.1. Biopower and the Politics of Life

Foucault’s concept of biopower concerns the biological existence of human beings and the mechanisms through which humans become an object of political intervention and strategy (Foucault, 1978). Biopower refers to the ‘techniques of power’ that manage and control the bodies of individuals (anatomopolitics) and the life of the population (biopolitics) (Foucault, 1978, 2008; Nadesan, 2008). The first pole of biopower, anatomopolitics, centres on the discursive construction of the body as a machine, disciplined through strategies that optimised its capabilities, extorted its forces, increased its usefulness alongside its docility and ensured its integration into systems of economic and political control (Foucault, 1978). The second pole of biopolitics moves out in scale from the individual body to the body of the population and focuses on the “species body - the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and

longevity, with all the conditions that can cause those to vary” (Foucault, 1978: 139). The emergence of biopower was marked by the proliferation of techniques, inculcated in schools, universities and military institutions, to subjugate bodies and control populations. The techniques also included the emergence of political practices and economic quantification linked to birth rates, mortality and public health (Foucault, 1978). Foucault suggests that (but does not detail how) the two poles are not antithetical but instead “linked together by a whole intermediary cluster of relations” (Foucault, 1978: 139). This thesis unpacks the ‘intermediary cluster of relations’ that Foucault notes as an assemblage of networked actors in order to emphasise intersections across the poles.

Biopower, fundamentally, asserts a relationship between the vitality of the state and the body of the individual and the population. Specifically, Foucault’s conception of governmentality considers linkages between the health of the population and the economic and political security of the state, and how these two, together, generate distinct biopolitical strategies for representing and acting upon populations (Foucault, 1978, 1998; Nadesan, 2008). Medicine forms one strategy through which states extend power into bodies of the population and of individuals:

[A]lthough medical technologies of government change across time, they tend to cohere around security problematics posed to, and by, the vitality, fecundity, and productivity of the population. Liberal regimes of medical government claim to optimize freedom by securitizing/regulating the conditions of life (Nadesan, 2008: 103).

According to Rose (2005), technological developments have generated new ‘economies of vitality’ as power can be more intimately inserted into bodies through medical technology at a molecular level. Similarly, this thesis suggests that vitality is increasingly entangled with the governance of biomedical technology and therefore requires a closer appraisal of the networked relationship that draws politics, people and technology together.

[The] vital politics of our own century ... is neither delimited by the pole of illness and health, nor focused on eliminating pathology to protect the destiny of the nation. Rather it is concerned with our growing capacities to control, manage, engineer, reshape, and modulate the very vital capacities of human beings as living creatures. It is, I suggest, a politics of ‘life itself’ (Rose, 2006: 3).

The term ‘politics of life’ was developed by Rose (2006) to contrast the political dynamics of our present with configurations of our past as theorised, principally, by Foucault (1978). Technological

developments, particularly linked to engineering vitality through biomedical developments, correspond with changing technologies of governance. According to Rose, biomedical technologies are “hybrid assemblages oriented toward the goal of optimization... These are not merely medical technologies or the technologies of health, they are technologies of life” (Rose, 2006: 17).

This thesis proposes that biomedical technologies like ARVs are more than their material form and reflect a broader politics of life: they assemble potent economic coalitions, political alliances, particular ways of thinking about disease and about health, modes of clinical care and practices of interaction between health care practitioners and patients. Foucault’s (1978) theory of biopower is productive for this thesis as it traces the relationship between the vitality of individual bodies and populations and the state; further, the ‘politics of life’ literature prompts us to explore how ‘life itself’ is conditioned through a complex array of forces that draw the state into the body through various technologies of governance that include biomedical technologies, as Rose (2006) and others (Rabinow, 1996; Raman and Tutton, 2010) have proposed.

However, reflecting Foucault (1978, 1991) and Rose’s (2006) call for theoretical agility that keeps pace with emerging technologies and shifting ‘politics of life’, this thesis engages with these foundational theories but also moves slightly away from a blanket application of these theories of biopower and ‘contemporary biopolitics’. It does so through the notion of biopolitical precarity, and articulates this argument in this chapter and across this thesis in dialogue with a set of contemporary ethnographic studies that have similarly prompted a nascent trajectory of thought on the ‘edges’ of biopolitics in health research.

2.2. The State of the Body: Embodiment

These literatures on biopower and the politics of life imply a particular way of thinking about embodiment: Foucault (1978) describes the state as ‘vitalised’ by governmentality, as animated through governmentality; the corollary, importantly, is the state’s management of vitality, as embodied by populations and individuals. Historically then, following Foucault (1978), the state of the body and the body of the state were tied together in a biopolitical contract of vitality. In this conceptualisation, states and bodies were positioned in relation to each other, fundamentally connected to and shaped through each other, but also distinct. Barad articulates the limits to this

distinction, in writing that, “for all Foucault’s emphasis on the political anatomy of disciplinary power, he too fails to offer an account of the body’s historicity in which its very materiality plays an active role in the workings of power” (2003: 809).

My research sought to not only look at how the body of the state and the state of the body are co-constructed, but to see how their boundaries are porous as they are networked into each other within a global assemblage. Specifically, by looking across the two dimensions – embodied and political – my research sought to understand how access to biomedical technologies might offer a productive way to think about the world inside the body (the embodied dimension) and the world outside the body (the political dimension), and where these distinctions of ‘inside’ and ‘outside’ might be usefully disrupted if we consider their boundaries as porous and the body as permeable.

As outlined in the previous chapter, this focus emerged from a history in which the state was implicated in the precarious lives of HIV-positive people as they died or became very ill without access to essential AIDS biomedicines; and it emerged from an interest to understand how people made sense of the state in their bodies through their experience of illness and resumed health as the biopolitical landscape of ARV access shifted with time. In this respect, my thesis follows a trajectory in medical anthropology (Lambert and McDonald, 2009; Strathern, 2009; Vilaca, 2009) that calls for a shift away from dualities in which the body is viewed as substrate for cultural symbols (Douglas, 1966). For, ethnographic research has shown how technologies that are constituted from human biological material disrupt distinctions between human and nonhuman, natural and cultural, self and other and generate new forms of life and biosocialities (Haraway, 1990; Jasanoff, 2005; Fairhead, Leach and Small, 2006 ; Strathern, 2009; Lock and Nguyen, 2010). Further, conceptualisations of governmentality that incorporate technological developments in pharmacology, genomics and neuroscience have shifted away from notions of bounded bodies and towards a conception of co-constructed entanglement (Rabinow and Rose, 2006; Rose, 2006; Raman and Tutton, 2010).

Rabinow’s (1996) work on biosociality is a calibrated way of thinking not only about how the state moves into and governs the body, but also about how – looking back out from the body – social relationships are formed around shared biological conditions. With the rapid unfolding of

technological developments and emerging anthropological work on embodiment, Lambert and MacDonald write that,

Given ... the origins of new transactions of human matter across body boundaries lie in scientific developments and technological innovation, especially in the medical realm, the juxtaposition of 'bodies' and the 'social' inevitably evokes many of the issues that were previously characterised by social scientists as concerning 'science and society' (2009: 11).

The term 'biosociality' reflects the joining together of these two spaces – the biological and the social – and emerges from research conducted by Rabinow (1996) through the American Human Genome Initiative. He describes how, with time, individual and group identities will be formed around this 'new genetics' where an increasing awareness of their genetic predisposition to ovarian cancer or neurofibromatosis, for example, will precipitate the formation of social groups around this shared biology:

In the future, the new genetics will cease to be a biological metaphor for modern society and will become instead a circulation network of identity terms and restriction loci, around which and through which a truly new type of autoproduction will emerge, which I call biosociality (1996: 186).

Following Whyte's assertion that "Biosociality is not a given, but an empirical question," (2009: 12) my ethnography prompted a rethinking of biosociality and its biopolitical antecedents. By looking across the two dimensions, the political and the embodied, it became apparent that any biopolitical analyses would need to pay attention to the context in which people live their everyday lives; and therefore it would need to pay attention to inequality.

The importance of bringing inequality into focus emerges from a set of very recent ethnographies on ARV programmes in Tanzania, Kenya and South Africa. Together, these ethnographies challenge a neat mapping of biopolitics and the politics of life on people's lives 'as they are lived' (Marsland and Prince, 2012). In their reflections on the genealogy of biopolitical theory above, Prince (2012), Marsland (2012) and Fassin (2009) ask whether the politics of life literature relies on assumptions generated in the global north where biomedical technologies, in particular, are more freely available than they are in the global south and therefore have different outcomes on whether people live or are, without access, 'left to die'. They suggest that this literature may also place an unfair emphasis on the (neoliberal) discourse of choice that locates responsibility for vitality on the individual, and shifts attention and resources away from addressing underlying

inequalities that affect the kinds of lives people live even when they are able to access ARVs as ‘technologies of life’. Marsland and Prince argue that,

Despite Rose’s own disclaimers to the contrary (e.g., 2007:64), he tends to argue for a rupture—between a ‘politics of health’ in the 19th century and ‘politics of population’ in the 20th century to a ‘politics of life’ in the 21st century (2007:3). He implies a chronology, in which the politics of health and populations are placed firmly in the past (2012: 456).

These ethnographies, which are discussed across this thesis, ask empirical questions of this chronology and suggest instead that the politics of health, population and life are entangled, and rather than denoting punctuated periods in history, that they run alongside each other in the present. For many HIV-positive people, the daily effort of sourcing food or even money to buy electricity for a fridge in order to ‘correctly’ store certain ARVs, complicates the framing of AIDS biomedicines as sufficient for sustaining life.

The politics of health of populations cannot, therefore, be divorced from the provision of the medicines simply because they are cast, in Rose’s (2006) terms, as ‘technologies of life’. For example, in Prince’s (2012) research with an ART programme in Kisumu, Kenya, we learn from MamaLouisa that her granddaughter, Risper, is only able to take her medicines in the evening (and not twice a day) because that it is the only time there was food for her family. Staff at Risper’s health centre paid attention to whether or not she was adhering to her medicines, but they did not (nor could they) address the extreme poverty and food insecurity that Risper’s family navigated in the broader context of life beyond HIV illness and its medicines (Prince, 2012).

This brings us back to the question of inequality that these ethnographies raise for the ‘politics of life’ literature, and the issue of responsibility:

Although [healthcare professionals] provide medicine and checkups, they expect people to manage their survival by proper adherence and forms of self-care. Like MamaLouisa, people learn what it means to be a ‘good’ client... They learn that failure is the fault of the patient... The focus on ‘positive living’ and the management of the self through becoming a ‘responsible’ client overlook the structural conditions shaping a person’s ability to adhere to or thrive on medication (Prince, 2012: 541).

Like Prince, anthropologists in Burkina Faso and Côte d'Ivoire (Nguyen, 2010), Tanzania (Marsland, 2012), South Africa (Morris, 2008; Le Marcis, 2012) and Brazil (Biehl, 2006), have shown how

governmentality operates when AIDS medicines are provided on the condition that people agree to 'live positively'. When ARVs were first provided in South Africa, for example, people were required to sign contracts with health centres in which they commit to adhering to their treatment and to following other 'healthy living' modalities, like reducing alcohol consumption and practising safe sex (Merten, Kenter, McKenzie, Musheke, Ntalasha and Martin-Hilber, 2010). These ethnographies suggest that not only are the medicines a technology of government (as they are taken into people's bodies to secure their embodied vitality) but they are also a disciplining technique through which bodies are governed. This dynamic, in which people access life-saving medicines but also agree to configuring their daily lives to continue qualifying for them, places emphasis on the individual and shifts the focus away from structural socio-economic conditions that may constrain their ability to 'live positively'. Therefore, in addition to considering biomedicine as a 'technology of life', this thesis also considers the uneven terrain in which AIDS biomedicines enable life, and the context and constraints that affect the kind of life that is possible for HIV-positive people to live.

The second 'empirical question' that these ethnographies and this thesis asks of the 'politics of life' literature relates specifically to biosociality and differentiation. Reflecting on her research in Tanzania, Marsland (2012: 457) writes that although biosociality is useful in thinking about the "new social groups that are brought together through their HIV status" it does not sufficiently account for the experiences of "those on the margins or out of the reach of this biopolitical life". She suggests, instead, that people associate with each other on the basis of pre-existing social relationships and not only because of a shared biology; for this reason, she proposes a (bio)sociality in which we take sociality and locality as seriously as 'bio', and denotes the emphasis on relationships by placing biology in parenthesis. This thesis engages with the value of understanding that HIV, or any biological condition like Rabinow's (1996) example of autofibromitosis, is not necessarily the main way that people identify themselves or relate to other people who also happen to be HIV-positive.

I use the term 'precarity' to denote multiple axes of inequality in which the state and a set of global actors are implicated in people's embodied lives. In doing so, I suggest that the politics of life is not only a question of technologies through which governmentality operates, but that it is also a process through which inequalities are (re)produced and embodied. Further, I argue that to

move beyond binaries that separate the state of the body from the body of the state, we need to see how bodies (historically viewed as nature) are permeable, and co-constructed with politics and technologies (historically viewed as culture). To this end, I propose a reading of the body as permeable.

In using the notion of precarity, we move away, too, from privileging biomedicines and viruses, and the world within the body, as the only legitimate ‘local biologies’ (Bharadwaj, 2013; Brotherton and Nguyen, 2013b). This in turn enables an understanding that the embodied efficacy of ARVs through adherence is mediated, at times, by chronic unemployment and food insecurity where taking these potent medicines with food is simply not possible. Or it becomes more possible to see that susceptibility to HIV infection may be mediated by the biopolitical dynamics of structural violence, like poor sanitation and the increased risk of sexual assault. Therefore, when we diffract biosociality through a biopolitical lens that expands beyond biomedical technologies, it becomes possible to understand also the extent to which people embody poor health care, unemployment, and sanitation. This form of biopolitical embodiment, like access to ARVs, reflects the entwined relationship between bodies and governments. Further, it complicates a reading of agency that locates responsibility on the individual to navigate large-scale oppressive structures; in this thesis, and as I discuss below, individuals and groups coalesce around these ‘new generation struggles’ as they see and speak to the state through everyday forms of citizenship.

2.3. The Body of the State: Governance and Citizenship

The third area of literature unpacks the dynamics of governance and citizenship with a focus on imaginaries of the state and embodied dimensions of subjectivity that surface through multiple and intersecting citizen practices. This aspect of the literature relates to the political facet of the research focus and connects into the final two ethnographic chapters that explore, respectively, citizens’ conceptions of democratic governance and the transnational governance of AIDS biomedicine.

The ‘modern state’, according to Weber (2006), was developed in Western Europe in the 19th century with a dual institutional structure that managed processes of decision (politics, policy and state organisation for deliberation) and structures of bureaucracy (state mechanisms for policy

implementation). This conception of the state connects to the empirical trajectory informing Foucault's theory of biopower in which the 'modern state' works through policy processes and bureaucratic mechanisms to subjugate bodies and control processes of life. More recently, however, transitions in development and technology have prompted reappraisals of such conceptions of the bounded state that 'acts down'. In particular, economic reform agendas of the 1990s to roll back the state and privatise public services (see World Bank, 1989) came under vociferous criticism, and prompted new emphasis on democratic state-citizen relations and NGO-government partnerships (Stiglitz, 2003). Consequently, theoretical approaches to governance emerged where: multiple actors were recognised, the actors were understood to transect and move beyond monolithic bounded entities of state, corporation or civil society, and interactions within and across actors and entities pointed to blurred boundaries and the value of understanding networks of governance (Leach, Bloom, Ely, Nightingale, Scoones, Shah and Smith, 2007).

I use the concept of networked governance because it recognises porosity of state boundaries and opens up space for complicating interactions across a network of actors linking multiple and intersecting sites of engagement that move across scale from the global to the molecular. This conceptualisation is developed across the thesis as it traces networks spanning Brazil and South Africa around the politics of life and the governance of AIDS biomedicine, and reflects an emerging dialogue between political science and anthropology that recognises: the shift from government institutions to governance networks (Jordan, Wurzel and Zito, 2005; Brenner, Jessop, Jones and MacLeod, 2008); the importance of moving away from universalist descriptions of governance to understanding regional variations through empirical research (Parker, 2007); the necessity of engaging citizens to understand, through their eyes, how they perceive the state (Scott, 1999; Steger, 2008); the multiple levels of governance as it is networked across scales and spaces into people's lives (Biehl, 2007; Sum, 2008); the porosity of governance structures and the networks through which governmentality operates (Ferguson, 2002; Nadesan, 2008; Ferlie, McGivern and FitzGerald, 2012).

Moving beyond conceptualizing governmentality as disciplining techniques that act on the bodies of individuals (anatomopolitics) and populations (biopolitics), as described above, shifts in science and technology have also engendered new forms of citizenship as people 'act up'.

Just as political and economic changes are altering the contexts, arena and ways in which people perceive and act on citizenship rights, so too are scientific and technological changes and the new risks and opportunities they present (Leach and Scoones, 2005:15).

Leach, Scoones and Wynne (2005) highlight the subtle linkages between local and global forms of citizenship that destabilise static categories like the 'state', 'community' and 'public'; further, they suggest that researchers need to understand how citizenship is embodied and expressed through public action and in relation to issues of science.

Citizenship no longer conveys a universalist sense of inclusion or participation in a stable political community; neither does it suggest the possibility of developing claims organised around a relatively stable set of differences; nor, for that matter, can the term be made to conform easily to the living out of a series of socially constructed identity positions on the decentred social subjects (Ellison, 1997: 112).

This thesis considers citizenship in its most quotidian sense as it is embodied in everyday life; as such, it explores the multiple and mutable subjectivities that women strategically bring forward in different spaces (see Nyamjoh, 2007; Cornwall, Robins and Von Lieres, 2011) as they 'act up' and on the global assemblage into which their vitality is woven.

Biological notions of citizenship draw on and extend Foucault's theorisation of biopolitics and the networks that link governments and citizens around biological identifications (Rose and Novas, 2005), technology (Raman and Tutton, 2010) and responses to risk (Petryna, 2004). Importantly, theories of biological citizenship extend the scope and space of engagement from the nation-state to transnational practices and networks of governance.

A new kind of citizenship is taking shape in the age of biomedicine, biotechnology, and genomics. We term this 'biological citizenship'... Different citizenship practices can be seen in the increasing importance of corporeality to practices of identity, and in new technologies that intervene upon the body at levels ranging from the superficial to the molecular. A different sense of the importance of the 'bare life' of human beings as the basis of citizenship claims and protections bound up in contemporary transnational practices of human rights (Rose and Novas, 2005: 439 - 440).

However, in line with the poststructuralist approach to citizenship as a reflection of multiple and overlapping subjectivities, biological citizenship has been criticised for focusing on a narrow conception of identity linked to a single biological condition. Nguyen develops a theory of

therapeutic citizenship which expands on biological citizenship by considering the range of identities and coalitions that form around particular illnesses and treatments.

Therapeutic citizenship broadens 'biological' notions of citizenship, whereby a biological construct – such as being HIV positive – is used to ascribe an essentialized identity, as in earlier forms of eugenics and racial ordering. Therapeutic citizenship is a biopolitical citizenship, a system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies (Nguyen, 2005: 126).

This concept points to the growing transnational influence of biomedical knowledge and practice across transnational networks connecting human and nonhuman actors. Nguyen refers to a therapeutic economy which, too, has salience for my research because it considers that range of therapeutic options in a given locality, and the rationale that underlines patterns of resort through which these therapies are accessed (2005). Theories of biological and therapeutic citizenship, however, do not fully engage with the multiple identities that individuals may hold beyond 'biological' predicaments and corresponding therapeutic interventions (Pfeiffer and Nichter, 2008). Further, neither set of theories considers the embodied dimensions of subjectivity that may inform multiple and intersecting citizen practices beyond shared predicaments and therapeutic interventions.

Although I engage with these medical anthropological conceptions of citizenship, my fieldwork emphasised the importance of understanding 'everyday citizenship' as it is lived and embodied in the most quotidian sense (Robins, Cornwall and von Lieres, 2008; Cornwall *et al.*, 2011). The notion of 'everyday citizenship' speaks to Cornwall *et al.*'s (2011) call for a more nuanced understanding of particular contexts, or states, of citizenship as they unfold across time and in very different spaces.

Rather than seeking a unified definition of citizenship that covers all dimensions of human action, entitlement and belonging, we are interested in the everyday, and often highly contingent and improvisational, negotiations and performances through which people define and pursue their desires and aspirations (2011: 8).

Two pertinent imaginaries – how citizens see the state (Corbridge, 2005) and how states see citizens (Scott, 1999) – generate the "mutually constitutive nature of the citizen-state relationship, and the extent to which different kinds of states make different kinds of citizenship possible" (Cornwall *et al.*, 2011: 7). However, as Cornwall *et al.* (2011) argue, there is very little

consideration in prevailing research around governance and citizenship concerning the extent to which these imaginaries shape what it means to be a citizen. The thesis builds on these sets of theories in conjunction with the notion of biopolitical precarity, outlined below, in order to develop a deeper understanding of citizenship and governance as it embodied by HIV-positive women. By integrating an approach – through visual methodologies – that sought to ‘see’ and ‘hear’ how people imagine the state, this thesis aimed to address critique. It proposes, specifically in Chapter Seven, that by moving away from a governmentality approach that considers how the state exerts control in and through people and population’s bodies, it can become possible to explore how people themselves conceptualise and strategically navigate their relationship with the state.

This thesis therefore moves away from Weber’s (1984) description of the state as a monopolising legitimate force that rules through rational law to a more fluid understanding of the state as one: that holds, in South Africa, the legacy of history in its institutional apparatus; and that is mandated, through the constitution in post-apartheid South Africa, to address some of these legacies through its bureaucratic infrastructure. This thesis refers to the state with an understanding that shifting governments animate state institutions – like the health care infrastructure – through policies that, in turn, have embodied ramifications. This draws on Cornwall et al.’s (2011) call for closer attention to be paid to the trajectories of citizenship experience and considers, through the lens of performativity discussed below, how people engage with different subject positions over time to pursue particular (and shifting) socio-economic and political ends. As discussed in the following section, not only is South Africa’s contemporaneous state affected by its history, as held in people’s embodied memory and its institutions, but it is also networked into a regional and global set of actors.

2.4. Permeable Bodies: Assemblages and Actor Networks

As discussed above, this thesis builds an argument that precarity is networked into the permeable body. In doing so, it calls attention to the porosity of boundaries and the extent to which we need to work against binaries that reify and separate states from citizens, technologies from bodies, nature from culture, the past from the present. In making this argument, I engage with two principal concepts – assemblages and actor networks – across each chapter of the thesis. This

section therefore presents this core set of theories as they are central to the overarching argument and enable me to trace the networked threads that draw the global actors into an assemblage that is networked into the permeable body. Two further concepts become salient in Chapter Six, namely topologies and anamnesis; these theories are introduced briefly below, but because they apply to a specific chapter and not the whole thesis, these theories are outlined in detail in Chapter Six.

As discussed above, the literature on the biopower, governance and citizenship disrupt binaries that separate technologies and bodies, and citizens and the state. In order to understand how these actors are networked into an assemblage, I consider how Giorgio Agamben (1998c, 2005), and before him, Hannah Arendt (1958), understood this preoccupation of 'life itself' as co-constructed between the body and the state. Thereafter, I articulate the usefulness of the concept of assemblage, initially introduced by Deleuze (1986) and later interpreted on a global scale by Ong and Collier (2005), to show how vitality extends beyond this dyad. I then propose that actor network theory (ANT) assists a practical understanding of how heterogeneous actors become animate in this assemblage.

Agamben's (2005) conception of bare life moves the trajectory of thought on biopolitics forward by politicising Foucault's theories of governmentality (1991) and biopower (1978). Instead of recognising the link and describing the nature of the relationship between the state, described as the sovereign power, and the bodies of individuals and populations, Agamben (2005) points to an irreconcilable paradox in which one's life is both fundamentally sacred and utterly expendable. He uses the figure of *homo sacer* to illustrate that the autonomy of the individual over their body, their life and their death, is subject to the will of the sovereign; without autonomy over their body, their absolute vitality, citizens are never free and political liberties never fully realized. This is described, earlier by Foucault (1978), as a paradoxical outcome, "because of the manner in which the material life or death of the subject is doubled in the sovereign right of life and death... The physical body of the subject is therefore doubled in his relation to the will of the sovereign, in the same way that ... the body of the sovereign is doubled by virtue of his legal status" (Calarco and DeCaroli, 2007: 213).

In recognising the ‘zoe’ of sacred life, democratic politics dismantles homo sacer and reinforces subordination to sovereign power: “[E]very attempt to found political liberties in the rights of the citizen is, therefore, in vain” (Agamben, 1998b: 181). The trajectory of this particular line of thought moves back to Foucault (1978) and even further back to Arendt, as she identified (1958: 320 - 321) a growing preoccupation with what she termed, “the immortality of life itself” as a compensatory concern with the growing sense of individual mortality. This was particularly salient for Arendt in the period in and about which she wrote, just following the systematic, state-sponsored murder and persecution of Jews by Germany’s Nazi regime in World War Two. Foucault, as I discuss above, made the link between sovereign power and the biopolitical body even more explicit, as he wrote that, “the production of a biopolitical body is the original activity of sovereign power” (1998: 6).

The absolute power over life and death, as described by the above theorists, is both useful and problematic for the findings and argument of this thesis. Like the genealogy of work on biopower and the politics of life, it is useful as it speaks to the entwined relationship between governance, biotechnology and the circumscribed capacity of HIV-positive individuals to live. However, the asymmetry of power described by Agamben (1998c, 2005) and Foucault (1978, 1991) tips towards the autonomy, or the will, of the state and away from the autonomy of the individual body and population to determine their life and death. This contrasts, slightly, with this thesis as it emphasises the importance of understanding governance as networked and bodies as porous, each constructed through each other and both only partially able to secure their own vitality. We see, with emergent biosocialities (Rabinow, 1996; Marsland and Prince, 2012) and with the theories of therapeutic (Nguyen, 2005) and everyday citizenship (Robins and Von Lieres, 2004; Ong, 2005; Cornwall *et al.*, 2011), the value of looking more closely at how, and where, individuals hold agency and negotiate the fraught conditions of their vitality. The dual concepts of assemblages and networks enable us to explore how individual and collective actions, to manage precarious life, are constrained and enabled.

As discussed above, globalisation and technological developments have prompted a re-thinking of governance in which we recognize that the contemporary ‘body of the state’ is far less ‘sovereign’ and far more porous than it was – ontologically and epistemologically – at the time of Weber (1984), Arendt (1958) and Foucault’s (1998) theorising. Not only are the state and citizen porously

implicated in each other's vitality but their own lives form part of a much larger assemblage. The term 'global assemblage' was coined by Ong and Collier (2005) to capture this dynamic, and has been used to reflect on the conflicts and controversies of globalisation, as changes in technologies, bodies and governments precipitated and were precipitate by global-local transformations.

As a concept, 'assemblage' can be traced further back to its French origins: *agencement*. It was developed by Deleuze and Guattari (1986) to convey, as Callon explains,

[T]he idea of a combination of heterogeneous elements that have been carefully adjusted to one another... *Agencement* has the same root as agency: *agencements* are arrangements endowed with the capacity of acting in different ways depending on their configuration (2006: 13).

Through their interpretation of 'assemblages', Ong and Collier (2005) speak against either locating the 'global' in space or in its structural effects. By using the term 'global assemblage' they ask us to think about the composite relationship between space and effect:

An assemblage is the product of multiple determinations that are not reducible to a single logic. The temporality of an assemblage is emergent. It does not always involve new forms, but forms that are shifting, in formation, or at stake. As a composite concept, the term "global assemblage" suggests inherent tensions: global implies broadly encompassing, seamless, and mobile; assemblage implies heterogeneous, contingent, unstable, partial, and situated (2005: 12).

As a concept, 'global assemblages' challenge narrow approaches of citizenship that centre on a particular identity (or biological condition) and protected set of entitlements based on membership in nation-state. Instead, global assemblages reflect how "practice, entitlement and benefits are realized through specific mobilizations and claims in milieus of globalised contingencies. The movements of global markets, technologies and populations interact to shape novel spaces of political mobilization and claims" (Ong, 2005: 697).

In this thesis, and particularly in the final two ethnographic chapters on the political dimension of my research focus, I explore how the capacity of the state to provide life-giving biomedicine is contingent on an assemblage of actors spanning global coalitions, regional alliances, financial markets, national and provincial health institutions, health care practitioners, pharmaceutical dispensaries, transport networks, and so on. I propose that when biomedicine moves through

these channels from the global sphere in to the national repertoire of public health policy and resources, then individual lives are not only a function of sovereign will but a part of a global assemblage. I therefore use the term 'global assemblage' to denote this heterogeneous collection of actors that assemble around AIDS biomedicine and its technological possibilities for life in an era where the vitality of individual bodies reflects and implicates a network of global, national, local and molecular actors.

At the same time that Ong and Collier (2005) coined 'global assemblage' for a collection of articles by eminent anthropologists on the anthropology of ethics and technologies, George Marcus and Erkan Sarka were also, but more cynically, writing about the usefulness of this concept.

While not one of the prime or key terms of recent and past discourses of theory in the social sciences ... assemblage in its uses here and there is actually keenly symptomatic of one of the major, if not the major, thrust of critical social and cultural theory toward the emphasis on the modernist focusing of attention on the always-emergent conditions of the present (2006: 101 - 102).

Peck, Theodore and Brenner (2010) similarly argue that it is not enough to simply look at the nature of assemblages, but that we need to understand the factors that generate assemblages and, in turn, how these assemblages affect people's lives. In response to the critiques of 'global assemblages', Collier developed a topological perspective to describe how the singularity of an assemblage may relate to a broader pattern of correlations or topological space (2009). Collier returned to topology, describing it as a concept of the 'middle range', to show patterns of interrelationship among techniques, technologies and forms of power. Specifically, he explored how neoliberalism or advanced liberalism relate to social welfare and economic regulation in Russia's governmental apparatus. In doing so, he hoped not only to offer a particular example of a singular assemblage, but to show how an assemblage may point to broader patterns of correlations (2009).

Although Ong and Collier's (2005) use of assemblage is useful for this thesis for the reasons I outline above, I follow Marcus and Sarka (2006) and Peck et al's (2009) caution against an 'unthinking' application of assemblage by engaging with the tools offered through ANT to look at how assemblages take shape in people's lives. In line with Latour's (2005) assertion that we cannot simply look at the form that networks take, but need also to look at the associations that bring

these elements together, Collier (2009) similarly argues – specifically in relation to the evolution of governmentality in Foucault’s lectures – that we cannot only identify a form of the assemblage but that we need to extend our analysis to understand how this formation comes to take shape. This connects to the way I work with ANT as a tool to look at, and possibly interfere in, relations between actors and actants that generated the politics of life I observed through my fieldwork.

By drawing on the notion of actor networks (Latour, 2005), this thesis seeks, first, to trace the networked threads that permeate the embodied lives of the people I worked with, and second, to understand how these people also strategically negotiated these networks in order to secure their vitality. Actor networks reflect a complex cosmology that include human and non-human actants that: according to the principle of Irreduction, cannot be reduced to any other; according to the principle of Translation, are linked to each other through the work of mediation; and finally, according to the principle of Alliance, do not have an inherent strength but which gain strength through their alliances within more or less durable networks (Latour, 1988). Although ANT is often discussed in abstract terms, even referred to as a theory, it is in fact grounded in the very materiality of our everyday lives. As Law writes,

Theories usually try to explain why something happens, but actor network theory is descriptive rather than foundational in explanatory terms, which means that it is a disappointment for those seeking strong accounts. Instead it tells stories about ‘how’ relations assemble or don’t (2009: 141).

I find ANT useful as a way of thinking through the kinds of people, institutions, viruses and technologies (among others) that came together and affected each other’s vitality in my fieldwork.

I therefore use ANT to think about the actors (people and institutions) and non-human actants (HIV and AIDS biomedicines) and how they interacted with each other through an assemblage that moved from under the skin right into the global arena of pharmaceutical developments, emerging trade policies and contested intellectual property rights. Further, I work with actor networks on the understanding that it is not a theory, but rather a “toolkit for telling interesting stories about, and interfering in, those relations” (Law, 2009: 143).

My own thinking about HIV and ARVs as non-human actants follows the trajectory of thought, discussed in the rationale, around the social lives of things (Appadurai, 1988) and Whyte et al.’s

(2002) exploration of biomedicine as material medica. More recently, Michael and Rosengarten (2012) have looked at HIV prevention technologies, or pre-exposure prophylaxis (PrEP) as actants enmeshed in a web of relations. They consider two case studies (of the AIDS clock and accounts of randomised control trials) and explore how their “global reach weaves into various local contingencies, particularly localizing critiques that emphasize the conditions of infection and death, and local political protest against the clinical trials” (2012: 95). In the same way that I hope to show the linkages between actors that assemble under the skin, out into the national, regional and global policy arena, and then back under the skin, these authors argue,

[T]hat there are topological interconnections among these globalizing and localizing enactments... [W]e see how the globalizing of both the AIDS Clock and RCTs/ethics is localized in various ways, but also how such localization draws on ostensibly globalizing resources (2012: 95; 102).

In the following chapters I similarly trace the threads weaving HIV and ARVs, as non-human actants, between the local and the global and argue that, as nonhuman actants, they cannot be separated from the institutions, bodies, ethics, economics and politics that coalesce around the hope for life and the threat of death.

I draw the two facets of my research focus – the political and the embodied – together by tracing the routes that actants (HIV and ARVs) travel into women’s bodies, and by tracing the threads linking these actants into an assemblage of social relationships, health care systems and practices, national governments, regional economic coalitions and global trade agreements. The first two ethnographic chapters explore actants within the body: Chapter Four explores how HIV, as a non-human actant, moves along three pathways to enter women’s bodies and lives. Thereafter, Chapter Five considers ARVs as nonhuman actants and explores the dynamic intra-action of these two actants (HIV and AIDS biomedicines) within the arena of women’s bodies. Chapter Six, the metaphorical hinge around which the first and last two ethnographic chapters swing, connects the research facets through the dual concepts of anamnesis and topologies. These concepts apply specifically to this chapter and are explored in detail there. Chapter Six details how precarity is spatialised and how it shifts as people made sense of their illness and treatment through narrative recollections of their past. In the process of sense-making through anamnesis the women’s accounts were situated in shifting spaces and times; I refer to the conjunction of shifting space-time and memory as a topology and explore how these topologies are embodied. The subsequent

two chapters move further out in scale and trace the national, regional and global actors in the global assemblage that is networked back into women's experience of embodied precarity linked to HIV and AIDS medicines.

Assemblages and actor networks are not only conceptually useful, but they are also politically important: in using them together, they work against isolating politics from the body, and offer a set of tools to think usefully about the ways that actants and actors across scale, from the global to the molecular, are networked into an assemblage around the biopolitics of life. In doing so, I seek to trace the threads that draw these actors into a network, and to show how they are woven into women's vitality. Ultimately, these theories speak of connection and against the discursive construction of distance that relies on reified entities held separate through their pairing in dichotomies. If we think about bodies, governments and technologies as related and porous, then it is harder to not face each other and hold actors accountable for actions that ricochet across this assemblage and permeate people's bodies and their lives.

2.5. Biopolitical Precarity in the Permeable Body

If global assemblages show that entwined threads weave life from the global arena into and out of the permeable body, and actor networks describe how these threads come to be connected, we are still left with the issue of women's embodied experience of vulnerability as their vitality is, in varying degrees, contingent on this assemblage. In this sense, this thesis moves from Foucault's (2008) assertion that the vitality of the state and the vitality of the body are tied together in a biopolitical contract, to suggest that the body of the state and the state of the body are part of a transcendent assemblage that they are only partially able to negotiate. I explore this tension through the concept of biopolitical precarity.

Biopolitical precarity denotes the intersection of the embodied and the political facets of this thesis and foregrounds the overarching argument that biopolitics – with a focus on AIDS biomedicine – are shaped through an assemblage of actors networked into the permeable body in ways that implicate precarious life. Precarity designates,

[T]hat politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence,

and death. Such populations are at heightened risk of disease, poverty, starvation, displacement, and of exposure to violence without protection. Precarity also characterizes that politically induced condition of maximized vulnerability and exposure for populations exposed to arbitrary state violence and to other forms of aggression that are not enacted by states and against which states do not offer adequate protection (Butler, 2009: 2).

Recent ethnographies from Tanzania (Marsland, 2012) and Kenya (Prince, 2012) similarly iterate the importance of integrating an understanding of inequality when looking at access to essential AIDS medicines and the broader politics of life in which this access is enabled or constrained. Reflecting on these ethnographies in the discussion above, I indicated that when I use the term precarity, I am referring to the extent to which people embody multiple and intersecting inequalities as they manage precarious employment, as they navigate live electricity lines underfoot, as they use unlit toilets in the middle of the night. Further, by integrating biopolitics with precarity, I suggest that we draw political actors into view and understand how their actions, within this assemblage, affect people's ability to access newer biomedical technologies for themselves, affordable education for their children, and safe water and electricity for their households. In doing so, I argue that the context in which people live their lives on ARVs – as they take their medicines with or without food, as they remember to step over live electricity lines or are forced to use unlit toilets and risk rape – become embodied as forms of biopolitical precarity.

Therefore, I argue that HIV-positive women's lives are woven into a biopolitical assemblage that makes it more or less possible for them to be able to secure their own vitality. The dynamics of this assemblage generate particular sources of vulnerability for women that are embodied and experienced, for example, through side effects from old generation medicines or through the limits placed on life by limiting treatment possibilities in the public sector to second and not third line medicines. Therefore, in this thesis I use the term 'biopolitical precarity' with reference to Butler's 'precarious life' to denote the intra-action of actants that shape and are shaped by women's embodied experience of precarity in a biopolitical network that is threaded into the permeable body.

In considering Foucault's work on the interpenetration of discourse, power and the body, Butler (1989) describes the danger of constructing the body as a slate for inscription:

The body is a site where regimes of discourse and power inscribe themselves, a nodal point or nexus for relations of juridical and productive power. And, yet, to speak in this way invariably suggests that there is a body that is in some sense there, pregiven, existentially available to become the site of its own ostensible construction (Butler, 1989: 602).

With reference to the discussion on the limits of representationalism above, Butler too asserts the danger of separating out materiality (the body) and discourse (power). Drawing on feminist, queer, Marxist and science studies, and building on insights from Butler (1989, 2004b), Foucault (1978, 1986, 1998), Hacking (1990), Rouse (2002) and others, Barad (2007) issues a challenge to the metaphysical foundations of representationalism by offering a post-humanist performative account of the relationship between material and discursive practices. Butler (2009), Gregson and Rose (2000) and Haraway (1997) have similarly proposed a series of conceptual approaches that incorporate performativity in order to move away from representational accounts with regard to gender, space and science respectively. Performativity is defined as, “the citational practices which reproduce and/or subvert discourse and which enable and discipline subjects and their performances” (Gregson and Rose, 2000: 434).

I draw on the notion of performativity to explore how individuals embody, reproduce and subvert discourse through particular sets of strategies and tactics, with reference, too, to de Certeau (1984). In particular, I use using the concept of post-humanist performativity as,

[O]ne that incorporates important material and discursive, social and scientific, human and nonhuman, and natural and cultural factors. A posthumanist account calls into question the givenness of the differential categories of ‘human’ and ‘nonhuman,’ examining the practices through which these differential boundaries are stabilized and destabilized (2003: 808).

Further, this thesis integrates the conceptual approach of actor networks with performativity, and post-humanist performativity in particular, through the concept of intra-action (Barad, 2008: 174). Through this concept, I explore how bodies become the meeting place for HIV and AIDS therapies, or nonhuman actants in Latour’s terms (2005); the AIDS therapies, for example, disrupt distinctions or causal connections between the body they animate and the life they take on through this animation. As such, “[d]iscursive practices and material phenomena do not stand in a relationship of externality to one another; rather the material and the discursive are mutually

implicated in the dynamics of intra-activity” (Barad, 2008: 174). I use ‘intra-action’ in place of ‘interaction’ as the latter reflects the Newtonian legacy in which ‘things’, or actants, are constructed as determinant, stable, prior-existing and bounded (Barad, 2003). Intra-action, instead, reflects Haraway’s call for a material-semiotics that transcends (by connecting) the materiality of things – like medicines, bodies, viruses – and the discourses that shape them – like beliefs around health or practices of self-care, for example.

2.6. Conclusion

By drawing on these concepts, this thesis reinforces the importance of understanding the body as permeable, as neither material nor semiotic, but as a material-semiotic assemblage of networks. In this thesis, the permeable body refers, first, to the human body which holds life and refracts the politics of life linked to HIV and AIDS biomedicine. Second, it refers to a topology of actors that are networked together in a dynamic and shifting assemblage to generate and resist biopolitical precarity. However, even with these concepts that draw politics into the body and highlight its permeability, we are still left with the core issue: that women like Miriam live precarious lives as a result of the dynamics of the assemblage that are networked into their body. I therefore propose the notion of biopolitical precarity as a conceptual hybrid that not only reflects how networked assemblages move into, through and out of the body, but also foregrounds the implications of this networked assemblage in women’s lives.

3. Methodology

In Chapter One, I described how the shifting biomedical and political landscapes informed the rationale underpinning these two dimensions of my research. Together, these shifting landscapes not only prompted me to look into South Africa with ‘fresh eyes’, but they prompted me to ‘look out’ from South Africa as it became apparent that the lives of the people I worked with were networked into a global landscape where bodies and governments are porous, and where essential biomedical technologies move, or are blocked from moving, across their borders.

The conceptual framework explored, in turn, the sets of literature that reflect on the interface between the state of the body and the body of the state as they are drawn, porously, in each other’s vitality whilst also precariously networked into a global assemblage that they were only partially able to navigate. My ethnography built on this rationale and conceptual framework, and was an active search first to identify and then to find ways to get to know the key actors that were networked into this global assemblage. In this chapter I trace the ethnographic journey I undertook in this search to find and form relationships with actors in this assemblage.

3.1. Research Design

[E]thnographic engagement can help us chart some of the complex and often contradictory ways in which neoliberalizing health structures, moral economy, and biology are forged in local worlds where biotechnology and structural violence now exist side-by-side (Biehl, 2004: 125).

This thesis is based on multi-sited ethnographic research and encompasses a range of visual and participatory methods developed in conjunction with the people I worked with in South Africa. I conducted multi-sited research in order to locate South Africa, and the lives of the people with whom I worked, in a regional and global terrain; and I worked with visual and participatory tools, particularly participatory photography, in order to move away from privileging what is said and to move closer towards a more layered understanding of the quieter and perhaps less visible spaces of people’s lives.

Overall, I conducted ethnographic research in South Africa from October 2010 – July 2011 and in Brazil from August – September 2011. The research methodology was designed around the two research dimensions outlined in Chapter One. Through my fieldwork in South Africa I researched women's embodied experience of AIDS biomedicine and their political engagement with the state, and through my fieldwork in Brazil I located my findings on women's embodied experiences of precarity in South Africa within a matrix of networks that moved between the molecular and the global. Therefore, in this thesis, 'multi-sited' refers to the approach I took in my fieldwork to work across scale, from the local to the global, with women living in Khayelitsha, the activist organisation they had worked with, the actors and activists in Brazil to whom South Africa had looked during the struggle for ARVs, and the national and international policy actors who made decisions about these women's ability to access medicines that would enable them to live a long life.

I describe this approach to ethnography as 'connective' because it sought to identify how and which actors and actants were connected in women's embodied vitality linked to AIDS biomedicine. In the course of my fieldwork, I identified five primary sets of actors with whom I conducted research. I have delineated these actors into five groups for the purpose of clarity; however, these groups are interconnected, as reflected in the ethnographic chapters and overarching argument.

The table below reflects the primary groups and research methods used with each group. I could not use all the data I collected across my fieldwork and, as the table indicates, I chose to draw strongly on the ethnographic component of my fieldwork. All of the research I conducted was vital, and although it cannot all be included in this thesis, it was necessary for me to undertake research across these groups, beyond the core ethnography, in order to build up a textured understanding of the various sites – people, places and relationships – I observed in my fieldwork. Therefore, although I use research data from all the groups, I have been specific about where I reflect on these facets of research in each ethnographic chapter. The relative density of the findings from each group is calibrated against each chapter: black indicates exhaustive use of that group's data; dark grey indicates moderate use of that group's data; light grey indicates relatively limited use of that group's data.

Figure 3.1. Table of Research Groups, Methods and Fieldsites

	CORE ETHNOGRAPHIC GROUP	BAMBANANI WOMEN'S GROUP	MEN AND WOMEN ON ARVS	THE TREATMENT ACTION CAMPAIGN (TAC)	POLICY ACTORS
1. GROUP PROFILE	A group of ten women who had worked as AIDS activists; who were on ARVs; and who lived in Khayelitsha.	A group of seven men and women who had worked as AIDS activists; who lived across the Cape Town Metropole; and who had created two sets of body maps about their experience of ARVs.	Forty men and women who were on ARVs; who had not necessarily worked as AIDS activists; and who all lived in the Cape Town Metropole (predominantly in the Cape Flats).	Members of TAC's national office (in Cape Town) and provincial office (in Khayelitsha); predominantly with the group of researchers and writers working on Equal Treatment (ET).	Twenty policy actors (including academics, activists and policy makers).
2. RESEARCH METHODS	Ethnographic research; participatory photography and film; digital, social and journey mapping.	Body maps; life history interviews.	Life history interviews.	Participant observation as researcher and writer on ET for TAC.	Key informant interviews.
3. FIELD SITE	Khayelitsha, South Africa.	Cape Town Metropole, South Africa.	Cape Town Metropole, South Africa.	Cape Town Metropole, South Africa.	Cape Town Metropole, South Africa and Recife, Brazil
4. CHAPTER FOUR (PATHWAYS OF PRECARIOUSNESS)					
5. CHAPTER FIVE (NEW GENERATION STRUGGLES)					
6. CHAPTER SIX (EMBODIED TOPOLOGIES)					
7. CHAPTER SEVEN (SENSATE STATES)					
8. CHAPTER EIGHT (THERAPEUTIC GOVERNANCE)					

The first dimension of my research focus, namely the embodied ramifications of AIDS biomedicine, was explored through ethnographic research located primarily in Khayelitsha, South Africa. Over this period, my ethnography spanned all five groups of actors. I introduce them here briefly, and in more detail below. First, I conducted ethnographic research with a core group of ten women who had been AIDS activists, were on ARVs, and who were living in Khayelitsha. I worked most closely with this group, and their lives are the foundation of this thesis. Second, I conducted narrative interviews with members of the Bambanani Women's group; this group of men and women were on ARVs, had also been AIDS activists and had developed body maps tracing the effects of HIV and ARVs in their bodies in 2003 and 2011. My fieldwork with these groups of people, and with their families and friends, strongly informed the findings that connect to the first dimension of my research. As such, the first three ethnographic chapters centre primarily on their lives as I trace the pathways through which HIV came to enter their bodies, their evolving relationship with the government as citizens calling for the public provision of ARVs, and more recently, for a broader set of conditions to support life beyond access to these medicines.

The second dimension of my research focus, namely women's political engagement with the state around AIDS biomedicine, was explored through participant observation with all five groups of actors. In addition to working with the above-mentioned two related groups of men and women who were on ARVs and who had been activists with TAC, I also conducted research with a further three groups who provided insight into the political dimension of my research focus; I discuss the specific details on sampling, access and methods in the following section. The third research group comprised 40 men and women who were on ARVs, but who had not necessarily engaged as activists around AIDS biomedicine. By conducting narrative interviews with this group, I sought to work also with both men and women and with activists and non-activists, in order to understand whether the struggle to access AIDS biomedicine may or may not have shaped the way people perceived and engaged with the state. The fourth set of actors were networked around TAC, the organisation through which all those in the core group and in the Bambanani Women's group had engaged as activists. I conducted participant observation with TAC, principally as a researcher and writer for their Equal Treatment magazine. Over time, I observed how TAC was networked into a set of local, national and international activist organisations. I therefore also conducted fieldwork with the primary activist organisations that were linked to TAC in South Africa, including MSF, Section 27 and the Community Media Trust, along with numerous new activist organisations that have spun out of TAC to address the conditions of life for all people, and not only the essential biomedical

requirements to support life. Finally, I conducted 20 key informant interviews with activists, academics and policy makers in South Africa and Brazil in order to trace some of the policy dialogues taking place across the two countries, and more broadly in relation to the global governance of AIDS pharmaceutical trade and development.

I secured Ethics Approval from the University of Sussex's Cross-Schools Research Ethics Committee in order to conduct this research. In addition to following the guidelines entailed in this formal ethics approval, such as ensuring consent, confidentiality and anonymity, my approach to ethnography, and therefore the data, was informed by a commitment to conducting ethical research that foregrounds recognition of shared humanity (and vulnerability) between myself and the people with whom I worked. I conceptualise ethnography as co-constructed through the relationships I formed with people and institutions in the course of my fieldwork. The methods I used, and describe below, emerged from these relationships and I therefore refer to the people who form the core of this thesis as the people I worked with and not as research participants. I was committed to not simply entering the lives of the people I met and then leaving with their stories; I therefore worked to develop relationships where we entered each other's worlds, where we worked together, shared stories with each other, hung out in each other's homes, met each other's families and friends. Further, I do not believe that ethical research only relates to the period in which I conducted fieldwork; I designed this research to work against some of the subtle (and more overt) forms of ethical contravention that can and does occur in health research, and as I conclude my PhD, I have worked to write up this thesis ethically, ensuring that I represent the lives and stories that were shared with me, with accuracy and reflexivity. I reflect on some of the issues that emerged in my fieldwork around ethics and positionality in the fifth section of this chapter.

3.2. Multi-Sited Ethnographic Research

The focus of my research centred on women's experiences of AIDS biomedicine but, as outlined above, it explored how their lives were affected by actors across a network that moves between the global and the molecular. This focus, therefore, underlined the value of engaging in research that looks at interconnections, rather than discrete actors or sites, through multi-sited ethnographic research.

The value of multi-sited ethnographic research for tracing the global-local, and even molecular, routes that medicines travel into people's bodies and lives has been well

established by anthropologists whose methodological and conceptual approaches have also informed this thesis (Whyte, Whyte, Meinert and Kyaddondo, 2004; Nguyen, 2005; Biehl, 2006; Biehl, 2007). These ethnographies largely reflect one of two prevailing approaches to the formation of identity and subjectivity in relation to health, as identified and problematised by Whyte (2009). The first approach relates to a concern with biopower and subjectivity, and emerges from the work of ethnographers like Petryna, Nguyen and Biehl that places health identities in “the context of national history and global connections” (Whyte, 2009: 12). The second approach, that of the politics of identity, reflects a paradigm in which health and development are closely coupled, and individuals and groups emphasise rights linked to particular identity – HIV, disability, leprosy – in order to secure national and international resources.

In conducting an ethnography to explore the shifting (embodied and political) subjectivities and health through the lens of biopower, I was aware that, as Whyte (2009) cautions, I would run the risk of masking the complexities of lives lived beyond a single identity – as ‘HIV-positive’, ‘woman’, ‘on ARVs’. Further, I was conscious that I needed to not only look at how people made claims and secured resources by mobilising particular identities, but that their embodied subjectivities may also speak to deeply rooted forms of structural violence. As Whyte argues, “There is a danger that we lose sight of the political and economic bases of health in our concern with identity, recognition, and the formative effects of biomedical and social technology” (2009: 15). Rooting Marcus’s (1998) concept of multi-sited ethnography in contemporary reflections on subjectivity, Whyte (2009) advocates comparative ethnography as way to move out from a narrow focus on health in order to anchor people’s lives in their social, economic and political relations.

With these ethnographic approaches, and reflections on their relative limitations, in mind, I conducted a multi-sited ethnography that focused on connections between, rather than comparisons of, related sites. This ethnography is comparative to the extent that comparative ethnographies prompt us to really engage with the contexts of particular sites and their relationship with each other; but it was not comparative in the strict sense of identifying two or more sites with enough important similarities to warrant reasonable research on where these sites may also differ. I could not and did not wish to conduct a comparative ethnography of South Africa and Brazil, despite the many salient similarities in each country’s social, economic and political profiles and their very different national AIDS responses. I did, however, want to move away from an exceptionalist paradigm in which, as I described in the

introduction, the biopolitics of AIDS biomedicine in South Africa was regarded as entirely unique. In the introduction, I described, too, why I perceived this paradigm as problematic because it does not consider the porosity of governance across scale, and dislocates regional and global actors (like the EU, BRICS and WTO) from the implications they have on national government's capacity to discern and meet the vital needs of its citizens. Therefore, as a 'connective' multi-sited ethnography, I researched how multiple sites (global, national, local, molecular) are connected through a network of actors (bodies, viruses, medicines, families, homes, clinics, governments, trade agreements, pharmaceutical laboratories) in a global assemblage that has implications for women's embodied precarity.

The rationale underpinning this 'connective' multi-sited ethnography was twofold. First, I aimed to identify key actors and understand how they were networked into this assemblage in ways that challenged me to move beyond the paradigms I may unknowingly perpetuate:

A multi-sited ethnographic approach readily opens up for questioning ontological assumptions about what is assumed to be 'real' and fundamental, as well as epistemological assumptions about how we know what we know. One effect of this approach is to highlight the way in which scientists and health policy-makers, and publics are all caught up in cultural informed realities that are sometimes mutually reinforcing, and at other times divisive (Lock and Nguyen, 2010: 10).

Second, I conducted a multi-sited ethnography as it opens up space for moving beyond site-specific research and contextualising political responses to and embodied experiences of HIV and AIDS biomedicines not only across multiple geographic sites, but also through the relationships between multiple actors. Thus, while multi-sited ethnography entails documenting how large sets of forces impinge on local sites, it does not necessarily mean doing fieldwork in multiple sites (Marcus, 1998).

In an article that is still in press, Fassin (2013) reflects retrospectively on his own ethnographic research into HIV in South Africa. He proposes a form of critical multi-sited research in which we move beyond thinking about 'horizontal' sites that fit together into a single ethnography, towards thinking about 'vertical' sites in which multiple scales and locations intersect with each other. He describes this kind of ethnography as multi-layered. I recognise that the kind of terms we use to describe our research matters, and while my ethnography might well also be described as 'critical multi-sited ethnography', I suggest that we not only think of sites in relation to scales or locations, but also in relation to the people we come to know and the relationships we form with them. In the following section I introduce the site of Khayelitsha as

the primary location in which I conducted my fieldwork, whilst also moving out in scale to locate Khayelitsha within the Cape Town Metropole, the Province of the Western Cape and South Africa more broadly. In this section I contextualise the socio-economic and geographic landscapes in which the people with whom I worked navigated their everyday lives. Thereafter I introduce the people with whom I worked in each of the groups I delineate above, and outline the particular research methods that applied to each group, and across my ethnography. This second section also moves out in scale across the actors in these groups to encompass the fieldwork I conducted in Recife, Brazil.

3.3. The Field Site as Place: Entering Khayelitsha

While it may be located on the periphery of the Western Cape's economic centre – Cape Town's Central Business District – Khayelitsha has played a pivotal role in South Africa's political history. It was the first place where governmental and non-governmental actors (including the Provincial Department of Health, TAC and MSF) worked together to provide AIDS biomedicine through the public health sector. As people resumed their health, their testimonies about the Lazarus effect of ARVs further bolstered these activists' call for the government to roll out ARVs across the country (Robins, 2006). The space of Khayelitsha, therefore, holds a history that reflects the shifting biomedical and political landscapes I describe in the rationale: people embodied ARVs as renewed vitality which they used, as citizens, to bear witness to the precarious lives of all other South Africans who were also ill but who could not access these essential medicines. This particular confluence of history and space underpins the rationale for conducting fieldwork in Khayelitsha. However, just as the people with whom I worked travel around the Cape Town metropole and further out across South Africa's provinces, so too did my ethnographic research flow beyond Khayelitsha's borders.

Khayelitsha is a semi-formal housing area that lies across 45 kilometers of the Cape Flats in the Cape Town Metropole district of the Western Cape Province. Khayelitsha means new home in isiXhosa, the dominant language spoken in this area and indeed across the Western Cape and its neighbouring province, the Eastern Cape. Like the majority of the people I worked with, almost 62% of Khayelitsha's residents had, according to a study in 2011, migrated from the Eastern Cape to access better health care and education and employment opportunities. Khayelitsha's name speaks to its relatively recent establishment, in 1983, in the Cape Flats, compared to older townships like Nyanga and Crossroads. It was originally established by the

apartheid government as part of its programme to forcefully relocate large numbers of residents from these neighbouring areas in a quest to quash the rising wave of anti-apartheid resistance among residents aligned with the African National Congress (ANC) and the ANC-aligned United Democratic Front.

The Khayelitsha Development Forum (KDF), formed in 1994 by residents in Khayelitsha to document and improve the lives of people living in this area, describe the confluence of political ideology and socio-economic deprivation that bear witness to this history in this excerpt:

The establishment of Khayelitsha in September 1983, through a public announcement and proclamation, was a practical expression of the policy of separate development as advocated and implemented by the then minority government. The notion of fragmentation was integral to the establishment of the area, like many such townships created in South Africa. The predominant planning objectives applied to the development of Khayelitsha were containment and isolation. As a result of being a product of an ideological initiative and not a development agenda, Khayelitsha is situated far from the centres of economic opportunities being located approximately thirty kilometres from the Cape Town Central Business District. It is also located on land that is costly to develop and to inhabit as it has a high water table and unstable sandy soil.¹³

Overall there are at least 22 residential sub-sections comprising older formal areas (with basic brick homes) and the newer informal areas where most of the people I worked with lived (these areas include Site B, Site C, Nkanini, Makaza and Harare). Because of the mix of formal and informal housing, it is difficult to gauge the total number of people living in Khayelitsha. The most recent reliable estimate, published by the City of Cape Town in 2005, indicated that Khayelitsha's population is 406, 799 (DPLG, 2005). This same study found that, like the people I worked with, the majority of people (57.4%) live in informal homes (made from panels of corrugated iron and cardboard); 30% live in formal brick homes, with many built by the post-apartheid government's Reconstruction and Development Programme (RDP); and 7.3% live in informal housing in the backyards of brick homes. 69.3% of households consist of 4 people, or fewer, and 71.8 of all households earn below the Household Subsistence Level (HSL). This may correlate with the high rate of unemployment (54.1%), particularly among youth aged 15 – 34 who form the majority of Khayelitsha's population (45.6%).¹⁴ The first map (below left)

¹³ http://www.khayelitshahumansettlement2013.co.za/?page_id=2; accessed August 2013.

¹⁴ http://beta2.statssa.gov.za/?page_id=1021&id=city-of-cape-town-municipality; accessed June 2013.

indicates the boundaries of Khayelitsha and its position relative to the centre of Cape Town, and the second map (below right) shows the position of the Western Cape Province relative to the Eastern Cape Province.

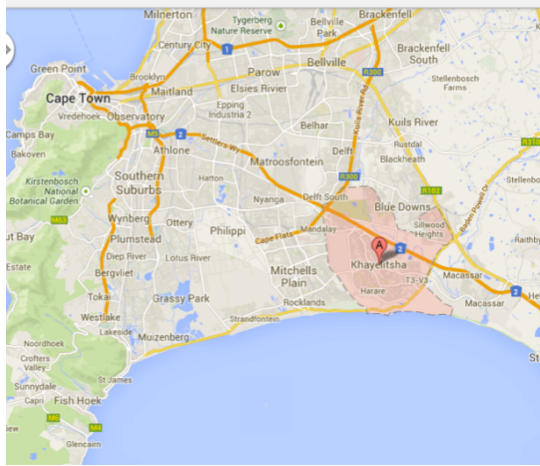


Figure 3.2. Map of Khayelitsha (Source: Google Maps)

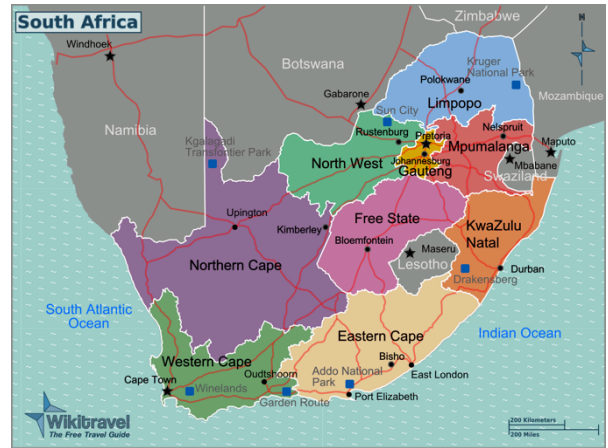


Figure 3.3. Map of South Africa (Source: Wikitravel)

When looking at Khayelitsha in relation to the Cape Town Metropole, and the province more broadly, the higher levels of poverty and unemployment affecting the majority of youth and households in this particular area are brought into stark relief: compared to Khayelitsha, the average rate of unemployment is significantly lower in the Cape Town Metropole (at 23.9%) compared to the Western Cape Province (29.9%).¹⁵ Zooming further out, unemployment in the Eastern Cape, where many of the people I worked with (and almost 62% of Khayelitsha's current residents) were born, has a higher rate of unemployment (50 - 60%) for those aged 20 – 24 (50%) and 15 – 19 (60%) years (ECSECC, 2012). The cost of living in the Eastern Cape was substantially lower than the cost of living in places like Khayelitsha in the Western Cape, but without access to basic employment or social grants, it was extremely difficult to withstand the grinding poverty in the Eastern Cape.

In my fieldwork, I found that many kinds of exchanges took place between households that were 'stretched', not only in terms of economic struggle among a group of people sharing a physical home, but stretched across kin in multiple homes across the country. This finding is not new, but reflects a trajectory of ethnographic research in the region. The notion of 'stretched households' was first articulated by Andrew Spiegel in research on household composition in Greater Cape Town, and in the former Bantustans (like the Transkei, now in the

¹⁵ http://beta2.statssa.gov.za/?page_id=1021&id=city-of-cape-town-municipality; accessed June 2013.

Eastern Cape) (Spiegel, Watson and Wilkinson, 1996). More recently, anthropologists also working in the Western Cape, like Fiona Ross, have traced some of the rapidly changing forms of domestic relationships (linked to urbanisation and migration, marital roles, economic hardship) that challenge notions of households as fixed (Ross, 1995). With the evolution of the HIV epidemic, research on the fluidity of household dynamics and composition have started to explore ways that households – stretched and fluid – manage the impact of HIV (Hosegood, Preston-Whyte, Busza, Moitse and Timaeus, 2007b). For example, Mark Hunter (2007, 2010) describes how greatly reduced marital rates in South Africa, combined with rising unemployment and socio-economic inequalities, are negatively affecting women in urban areas like Khayelitsha by placing greater responsibility on them to sustain single-headed households in a time of chronic poverty and illness.

Many of the people with whom I worked with had moved to Khayelitsha from the Eastern Cape, not in search of employment or education, but in search of life-saving AIDS biomedicine for themselves and their very sick children. This brings me back to the reason I selected Khayelitsha as the site of my fieldwork. As the place of MSF's ARV pilot trial, starting in 2001, Khayelitsha was a critical node in the network of actors that assembled around the struggle for AIDS biomedicine in South Africa. With the Provincial Administration of the Western Cape, MSF worked with TAC to set up this trial in Khayelitsha's three Community Health Clinics (CHC): the Khayelitsha (Site B) CHC; Michael Mapongwana CHC; and Nolungile (Site B) CHC.¹⁶ As I discuss in Chapter One, Khayelitsha was therefore an epicenter in the ARV struggle that brought together actors from across the country, and from across the world, together in an effort to compel the government to provide ARVs through the public sector. Therefore, by centering my ethnography in Khayelitsha with a group of women who had largely started ARVs through this trial, and who had been a part of this history of AIDS activism, I anticipated that I would be able to trace their relationship with some of these key actors and also with actors I could not know to anticipate prior to commencing my fieldwork.

3.4. The Field Site as People: The Research Actors

As I followed the lives of the people I came to work most closely with, my field site in South Africa became less about the space of Khayelitsha (where they lived), the Cape Town Metropole (where they worked), or even the Eastern Cape (where they grew up). Instead, my

¹⁶ http://www.westerncape.gov.za/eng/your_gov/305/facilities/6422; accessed August, 2013.

field site became more about a site of relationships in a network of fields where technologies, institutions, people, space, photographs, drawings, words and silences co-existed, crashed into and missed each other.

This is not to say that space did not matter; it was critical, and as such forms the focus of Chapter Six. But in relaying 'where' this fieldwork was conducted, I also hope to show, here and in the following chapters, how the spaces of my ethnography reflect time and the presence of history in these sites (Massey, 2005) and how these 'space-times' are generative of and produced through social relationships (Lefebvre, 1991). I discuss the relationships that were the site of my research below. Thereafter, I move out from South Africa, across to Brazil, where I conducted fieldwork in Recife, in Brazil's northeastern province of Pernambuco.

3.4.1. Ethnographic Research with Women in Khayelitsha

I did not know that my fieldwork would become more about relationships, and less about the space in which they took place, but perhaps I should have anticipated this when I sought Nondumiso Hlwele's advice at the start of my research. Nondumiso and I had worked together for almost eight years, and by the time I left to start my PhD, we had become friends. When I returned to Cape Town to start my fieldwork, I met Nondumiso and I asked her if she thought I was on track with the research facets I wanted to explore and the methods I had in mind to do this. She listened as I talked through my ideas; and then told me her thoughts about the relative risks and benefits of working with a group of people who had historically fought for ARVs, but whose lives now were much more of a daily struggle to feed, clothe and school their children. Nondumiso, too, had experienced this economic precarity, and wondered if the new era of collaboration between former activist organisations and the government had precipitated a fall in AIDS-specific funding to those same activist organisations and their employees and beneficiaries. This dynamic speaks to the shifts in the biomedical and political landscapes outlined in the rationale for this research: structural inequalities that were eclipsed by the vital politics of access to AIDS biomedicines remain in place and are even more visible in the wake of the rapid scaling up of these biomedical initiatives. Nondumiso's observation iterates emerging ethnographic research from elsewhere in Africa. For example, Ruth Prince's ethnography in Kisumu, Kenya, substantiates "the argument that the focus on keeping bodies alive with medicines may leave persons more vulnerable when humanitarianism or human rights discourses fill in for a politics that can address socioeconomic inequalities and pursue a political program of change" (2012): 555).

Further, we agreed that it would be worth exploring how people are living in this ‘post-ARV-struggle’ world because, as Nondumiso said, “Now, it’s not just about people dying”. It was only after this meeting that I felt slightly more sure-footed about the research focus and the route I would follow in conducting this ethnography. Nondumiso agreed to assist by introducing me to a group of women who had similarly worked as activists, who lived in Khayelitsha, and who were on ARVs but whose lives were, quite evidently, so much more than these characteristics. I trusted Nondumiso to be frank about me to her network of colleagues and friends and, because there was no financial incentive to work with me, that the people she eventually introduced to me would have a clear enough picture of who I was.

It was therefore through Nondumiso that I met the women whose lives would come to form the core of this ethnography. The ethnographic research I conducted with this particular group of women enabled me to develop an understanding of the intimate intricacies of their lives, and from this knowledge, to explore how they were networked into an assemblage of actors that moved from the molecular to the global. The networks I traced in my fieldwork were, in some respects, quite visible, but in other cases, they were less tangible and more elusive. In this instance, though, I formed relationships with a group of women who all knew Nondumiso, and each other. This allowed for a more textured ethnography where our relationships were multi-faceted, moving into each other’s, but the visibility of this web of relationships also presented a set of ethical dilemmas that I discuss in the section below. Further, the specific characteristics of this group of women, particularly as former AIDS activists, delineate the boundaries of this thesis in a number of ways that I reflect on below.

All ten women had worked as activists with TAC, were on ARVs and lived in Khayelitsha. These basic criteria were important for me to be able to trace the connections between the two facets of my research – namely, women’s embodied experience of ARVs and their political relationship with the state as citizens. These initial criteria were also practically useful as a way for Nondumiso to identify, from a very large group of colleagues and friends, a group of women who might be prepared to work with me. Although I had planned to work with a group of women with these predefined characteristics, they quickly slipped away from the surface of our interactions when we were hanging out. It was their embodied life, and not any single (often externally imposed) identity, that mattered. Therefore, although this group of women share a number of characteristics that I had identified in order to focus my research, the way we worked to co-construct this ethnography rendered labels like ‘HIV-positive person’ and

‘research participant’ redundant. As far as possible in this thesis, I avoid descriptions like ‘people living with HIV’, or ‘HIV-positive man’ or ‘HIV-positive woman’: it was everyday life, and not any single identity, that I was most concerned with. This is not a matter of semantics, but a matter of ethics. Just as this research traced the routes through which actors are networked into each other’s vitality and into women’s bodies, my fieldwork became a site of mutual accountability.

I met Miriam first. Her text message pinged onto my phone in November 2010. It said, ‘Call me’. I did, and we met two days later. In the first ethnographic chapter I introduce her and all of the women in this core group in detail, so here I will relay the way we came to know each other and how we worked together in my fieldwork.

In this first meeting we had talked about the ethical parameters of working together, and the kinds of things I hoped to work on with her, like using photographs and film as a way of sharing important parts of her life with me, drawing social maps of her close family and friendship networks, and just hanging out together (I discuss these methods below). It was after this initial exploratory meeting, sitting quietly in the car and listening to the station she had found for us on the radio, when she said, “Ya, ok. Let’s do this. But you should know that there are some dark things I don’t like talking about”. I was concerned about drawing out sadness in my desire to understand the women’s lives, and their histories, and Miriam prompted me to address this from the outset. I committed the following three things to her, as I subsequently did with all the people I came to work closely with. I said that I would be careful to not ask too many questions. Miriam then suggested that we could also write to each other in a diary in the times between hanging out, and this, along with the photostories, came to be an important thread of our fieldwork conversation. Second, I proposed that, if she wanted, I would tell her about my life, that we could hang out in my home as well as hers, and that I would introduce her to my family and friends, and not only ask to be taken into her world. Finally, I said that I did not view this as a time-bound ‘research relationship’, and committed to staying in touch with her, if she wanted this, when I returned to England to finish my PhD. We had reached the taxi station at this stage, and I had double-parked as cars sped past us, hooting. Miriam sat next to me, in no apparent rush to get out of the car, laughing. “Yoh! Nondumiso said that you’re an odd one. Now I understand.” Miriam turned the radio up for my journey home and opened the car door, bemused by my confusion. As she climbed out the car, she said, “I’ll see you soon. Call me”.

Over the next few weeks, I met each of the other ten women I came to work most closely with. Miriam works with five other women in the core group in an NGO called *uYaphi*, located in one of Cape Town's wealthier suburbs called Obs. Through a combination of Nondumiso's initial contact followed by Miriam's affirmation, I was contacted by Brenda, Sigbongile, Thandiswa, Zolani and Yandisa. We each met to talk about whether and how we might work together. In this slightly more formal meeting, before we started 'hanging out', we both signed a consent form. In it, I agreed to the specific terms they had stipulated for our relationship (such as the ones I describe in Miriam's case above). The form also included a set of ethics criteria that I agreed to follow, such as my commitment to confidentiality and anonymity in all the forms that their work (in photographs, films, maps) might be represented in this thesis. The ethical parameters of my relationship with all the people I worked with was an evolving conversation that spanned the duration of my fieldwork. It has continued, in some cases, in the last two years as I have written this thesis and have needed to consult the women with whom I worked about unanticipated questions of representation and forms of acknowledgement (research ethics are discussed in detail below).

Miriam, Brenda, Sibongile, Thandiswa, Zolani and Yandisa earn their main income through *uYaphi*, which was set up in 1994 to enable HIV-positive women to earn money by making paper-mâché bowls, dustbins, plates and beaded AIDS ribbons. Their much contested and meagre income in this NGO was supplemented by two main social grants; all the women working at *uYaphi* also claimed child support grants (R280/month) and Yandisa and Miriam claimed disability grants (R1, 200/month) that they had respectively secured five and six years previously, when they had been ill with tuberculosis. In order to continue to claim these grants, the women agreed to *uYaphi*'s business model in which they would be 'self-employed' and therefore still eligible for their grants but not eligible for any form of employment protection through this NGO. Their income from *uYaphi* fluctuated from R500 to R1, 500 each month, and was often thought to be down to the whim of the income generation manager and his 'good will' or, more often, his ill will when the women challenged his business ethics. Nondumiso also introduced me to four colleagues whom she had also met through TAC, initially, but with whom she had worked subsequently in affiliated HIV organisations. In this way, I came to know Zama, Yvonne, Lilian and Sindiswa. Zama and Yvonne worked together as treatment literacy practitioners for an HIV media organization. Lilian and Sindiswa worked as researchers on a large-scale survey, run through an academic centre in Cape Town. Each of the women had at least one child, and with one exception, all headed up their own homes in Khayelitsha.

Despite entering my fieldwork with an idea of the people I hoped to work with, and the methods I planned to use, as I worked with this group of women my ethnography took on a life of its own. It was only possible to really get to know the women I worked with by hanging out with the people who mattered to them, in the places they were prepared to take me into and show me. This entailed 'deep hanging out' (Geertz, 2001) in anthropological terms. In practical terms, it meant that I walked alongside their lives: learning about paper mâché bowl making; travelling the routes they travelled and getting to know the people they spent time with as they moved between their home, work and clinic; taking care of their children while they worked or while they waited in the long monthly line to withdraw their grant money; attending court cases, media briefings, parliamentary pickets, marches, health check-ups; witnessing birthdays and births, funerals and deaths.

In addition to participant observation, informal conversations and life history interviews, I used a set of visual research methods including participatory photography and film, and actor network mapping (Kolb, 2008; Dennis Jr, Gaulocher, Carpiano and Brown, 2009; Prins, 2010). For my research, the participatory photography (Poletti, 2011; Allen, 2012) and film (Kindon, 2009) methods entailed providing digital cameras for each of the ten women and working with them to document, for example, where they felt the absence or presence of the state in their lives. The photographs took me into parts of the women's lives that would have otherwise been extremely difficult to access including, for example, stick fighting ceremonies that marked the transition of one woman's family member as he re-entered the family village from the mountains where he had been circumcised in the Eastern Cape. Together we collected over 3,000 photographs and about 100 gigabytes of digital data including film.

Actor network mapping entailed working with a set of visual methods in conjunction, at times, with life-history and narrative interviews in order to develop a fuller sense of the women's lives, kinship networks, affective relationships and organisational associations. To this end, I worked with the core group to develop a set of journey maps (tracing the woman's life from her birth to the present moment), social maps (showing family relationships and the spaces of homes, for example) and digital maps (using Google earth and layering stories and photographs on to space) (Campbell and Gregor, 2004). These methods, together, enabled me to conduct ethnographic research beyond what was said, to understand how meaning is made in and through practices (Kleinman and Kleinman, 1994; Cornwall and Gaventa, 2001), senses (Csordas, 1994) and space (Galvao, 2005).

3.4.2. Narrative Life History Interviews and Body Maps with the Bambanani Women's Group

Second, I engaged with a group of seven people (one man and six women) with whom I have worked in various capacities since 2004. In my thesis, I reflect on the narrative life history interviews (Gilsenan, 1994; Hurwitz, Greenhalgh and Skultans, 2004) with this group in conjunction with a series of body-maps that they created in 2003 and 2011 (see Cornwall, 2002a; MacGregor, 2009b). I was invited by the group to participate in the series of workshops in which the 2011 set of body-maps were developed by the artists with the support of Jane Solomon, who had developed this particular method and worked with this group in 2003. The 2011 workshops included a set of 'visual enquiries' that I proposed to the group (including creating an 'ARV timeline' and showing where they 'felt' medicine in the body) which I then explored in greater detail through narrative and life-history interviews with the artists.

These body-maps represent a trajectory of activism through art in which the embodied ramifications of ARVs and HIV are made explicitly visible; in 2003 the positive effects of ARVs were made visible as a means to compel the government to provide AIDS biomedicine (MacGregor, 2009a). In 2011, the body-maps bear witness to the longer-term implications of medicine, and of a longer life. These body-maps therefore enabled me to explore continuity and changes between the original 2003 and then the 2011 art works with regards to the politics of representation and new generation struggles linked to accessing AIDS biomedicine. Like the women in the core group, all the members of the BWG had engaged with TAC in the struggle for AIDS biomedicine and many of the people in this group were friends, or colleagues, of the women in the core group.

This is an example of the limitations of imposing distinctions on the groups with whom I worked, as the connections between them were far thicker than the boundaries distinguishing them. Although I refer to my fieldwork with these two groups most strongly in this thesis, I have distinguished between them because although I had worked with the BWG for over eight years, our relationship had largely been professional. I explicitly sought to move away from this potentially unequal and historical dynamic by forming relationships with the women in the core group that were much more about hanging out than they had ever been with the BWG.

3.4.3. Narrative Life History Interviews with 40 Men and Women on ARVs

Third, I conducted 40 narrative life history interviews (Cole and Knowles, 2001; Bernard, 2011) with men and women who were receiving ARVs but who had not necessarily been involved as activists in the struggle for ARVs. While I sought to understand women's embodied accounts of AIDS biomedicine and their perception of and engagement with the state as citizens, I also decided to extend my research to incorporate both men and women, and both activists and people who had not been activists. The focus of my ethnography remained with the core group and the BWG described above, but I also recognised during my fieldwork that I was working with a very particular set of people and that for my research to have broader validity beyond the narrow focus on women (who were activists and on ARVs) I would also need to engage with men and with people who were not activists. I therefore, again with Nondumiso's help, identified a group of people who lived in the Cape Town Metropole (and were not necessarily living in Khayelitsha); who were on ARVs through the public health sector; and who had not been involved in AIDS activism.

I worked with Nondumiso and a colleague of hers, Penina Dlulane, to identify a group of 40 people (22 women and 18 men). Nondumiso, Penina and I worked over three months, from April – July 2010, to conduct the interviews. We stopped at 40 interviews because I was able to see sufficient triangulation of key findings around health and citizenship in my preliminary analysis of the interviews; and because this was an ancillary part of my fieldwork that I included to substantiate and deepen my ethnography. Both Penina and Nondumiso are trained researchers, and they had also both expressed a wish to conduct research and to receive further training in research conceptualisation, interviews and analysis. We therefore worked together to establish the sample criteria and the interview schedule. The sample criteria were basic: we sought to identify a group of men and women, aged 20 and above, who lived in the Cape Town metropole area, and who were on ARVs. I developed the interview format, and met with Nondumiso and Penina to finalise the specific content of the interview schedule. They made me aware, for instance, that it might be difficult to ask questions about family members as this could bring the loss of relatives (due to AIDS) to mind. We removed all direct questions that explicitly explored kinship, and asked much more general questions about people's recollections of important parts of their lives. Prior to commencing the interview, we went through a detailed process of describing how the research material would be used. In this form, I outlined the purpose of my research, noted that I was a PhD student at Sussex University, and that my research had been approved by Sussex University's Ethics Board. I also committed to absolute confidentiality, to anonymising all the respondents' names, and to

removing any identifying characteristics from my thesis. These written consent forms were signed and dated by myself, Nondumiso and Penina and by the person we interviewed.

We created the interview format to privilege narrative over structure, and were careful to avoid closed-ended questions, or questions that implied that there was a 'right' or 'wrong' answer. In fact, we all tried to avoid questions altogether. To this end, I drafted a set of open-ended 'prompts' that enquired about the respondents' lives across time. All interviews were, with consent, recorded and then transcribed. In the interviews I asked the respondents to take me back to the time they wished to speak about and did not insist on particular parameters for when 'life started' in their narrative account of their history. After learning about their family, where they grew up and their most important recollections from their history, I then asked each person to think about their life as a series of chapters in a book, with each chapter reflecting an important set of events. Here, too, I did not want to 'fish' for information about contracting HIV, becoming ill with AIDS and starting ARVs; instead, I was interested to hear whether accounts of 'bare life' were still salient for people at a time when ARVs were almost universally available through the public health system. In this way, I sought to contrast the accounts of the women with whom I worked in the core part of my ethnography with those accounts of men and women who may have started taking ARVs in the aftermath of the activist struggle to bring these medicines into South Africa's public health system.

Once the interviews were transcribed, I entered them into *nVivo*, a qualitative software programme, and analysed their key findings. The large quantity of material held in these transcripts meant that I could not work intuitively to draw out the main themes; I needed to use this software in order to work through the interviews (sometimes they were an hour long) in a systematic way. It took a month to code this information and although most of this material is not in the final version of the thesis, it was critical for me to have conducted this additional research. It enabled me to feel confident that my ethnography was situated in a broader context and that my overall findings in this thesis incorporated an informed understanding of the current political and biomedical landscape. While I do not use large tracts of these interviews in the thesis, I would like to return to them, if possible, in the future, as they not only spoke to Chapter Seven's discussion on governance and citizenship, but to a complex set of concerns around generations of love and loss that preceded them; around perceptions of fatherhood and their own absent fathers; and around expectations of masculinity that both men and women felt were restrictive to creating equitable social and sexual relationships.

3.4.4. Participant Observation with the Treatment Action Campaign

Fourth, I conducted participant observation with the Treatment Action Campaign (TAC) throughout my fieldwork in South Africa as a writer and researcher for the Equal Treatment (ET) magazine. As discussed in Chapter One, prior to commencing my PhD I had worked at the University of Cape Town and this included working historically with TAC and the former Health Minister. For my PhD, I aimed to start from a different point, away from the historic ties of activism and academia, and to enter new (and also old) relationships as a student. I was (re)introduced to TAC by a friend of mine, Mara Kardas-Nelson, who had worked with TAC on their magazine, and offered to introduce me to ET's editor. It was through this connection that I was able to enter TAC. TAC's General Secretary, Vuyiseka Dubula, and ET's Editor, Marcus Louw, formally authorised my work with TAC and I was brought into TAC's National and Provincial office as a student researcher.

ET is distributed to over 55, 000 people in South Africa, and this publication is the principal method that TAC uses to convey information on HIV science, AIDS medicines and prominent national and international policy developments to its members. Working on ET therefore enabled me to understand the critical policy debates taking place between activist coalitions (within and beyond South Africa), and between the South African government and global actors (including the Global Fund). It was also a critical opportunity to feed the emergent findings of my fieldwork back into these policy and advocacy processes. Findings from my fieldwork were used to provide empirical evidence to support TAC in their policy advocacy around addressing side effects of older medicines, for example, or on Brazil's SUS health system and the lessons South Africa could learn from Brazil in developing its own National Health Insurance policy.

I worked with ET's editor and researchers on all five issues of ET that were published over (and after) the course of my fieldwork. The issues covered both dimensions of my research focus and looked at, for example, the embodied ramifications of old and new AIDS and TB medicines, alongside the political and policy barriers to bringing better and cheaper drugs in to South Africa. I list the title and theme of each issue below:

1. Equal Treatment Issue 37: Bridge the Divide (National Health Insurance policy advocacy).
2. Equal Treatment Issue 38: Drug Resistance (adherence, side-effects, drug resistance).

3. Equal Treatment Issue 39: Who Does the Caring? (Health Care Workers policy advocacy).
4. Equal Treatment Issue 40: TB Can Be Cured (scientific developments in TB treatment).
5. Equal Treatment Issue 4T: Fix the Laws (generic and patent policy advocacy).

The publication of each ET issue entailed multiple steps including: brainstorming and developing the theme of each issue; conducting reviews on policy and related literature as background for each issue; conducting empirical and policy research for my assigned articles; final edits and developing the visual layout for the articles and the overall issue.

In addition to working on these steps with ET, and with its digital graphics team, I also worked with the women from the core group and the BWG, along with some of their friends, who had said they wished to develop their writing skills. In particular, Nobuhle Qabazi, a friend of Nondumiso's, was interested in becoming a journalist, and so together we conducted informal interviews with our friends about the embodied effects of AIDS biomedicines and wrote an article about the need for South Africa to change its outdated patent legislation in order to enable the government to provide better biomedicines to its HIV-positive citizens (below right). I also worked with TAC members in other provinces to write articles for the magazine, and the article (below left) on the reasons people stop their ARV treatment was written with Thandeka Vinja, in the Eastern Cape, and with Nondumiso and myself.

My work with TAC, therefore, was a central aspect of my fieldwork, as it enabled me to

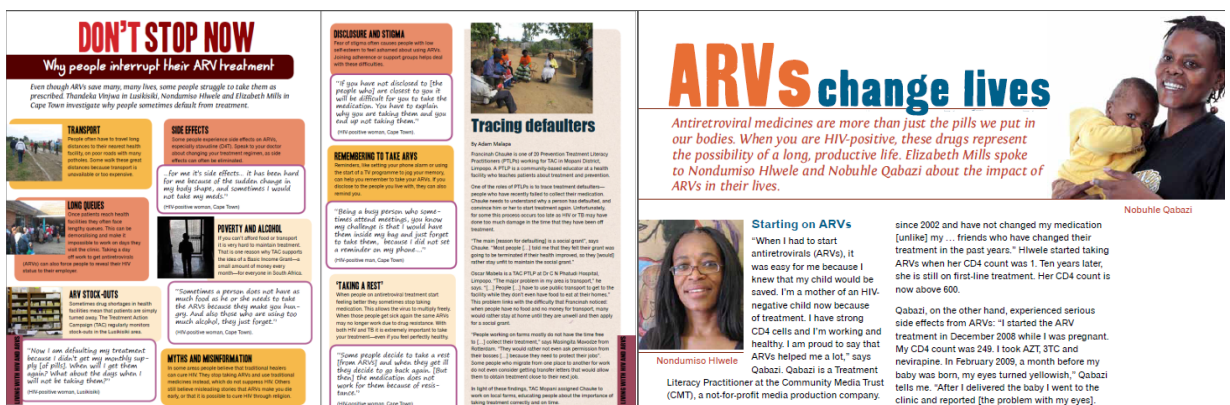


Figure 3.4. 'Don't Stop Now' Article in *Equal Treatment* (Source: TAC, 2011)

Figure 3.5. 'ARVs Change Lives' Article in *Equal Treatment* (Source: TAC, 2011)

understand contemporary policy dialogues between activist organisations and the government, and because it offered a platform for myself and my colleagues to feed our research and experiences back into TAC's activism through the articles we wrote. I was also able to learn fine-grained details about TAC's organisational structure, its internal politics and the people who worked there. I do not include this information in the thesis as I agreed to

participate in confidential meetings on the condition I excluded this material from my thesis. I am also aware that even though I received consent for conducting participant observation, there are inevitably conversations where privacy and confidentiality is assumed, without explicit agreement.

Working in TAC also, unexpectedly, seemed to offer me some level of ‘credit’ when I first met the core group of women with whom I worked. Although I was working in TAC at a different time to the period in which they had worked with TAC as activists, we could both reflect on our perceptions of the organisation, of its historic role in both of our lives, and of its changing role in South Africa’s shifting political landscape. Within TAC, however, I was sometimes confronted by the challenge of appropriate language when discussing what I describe in this thesis as ‘new generation struggles’. My research was, in part, an exploration of the ‘grey space’ of medicine, where it may not be embodied as an entirely positive outcome of the activist struggle. Because there were still significant struggles around access to new forms of medicines in South Africa, my research on embodied ambivalence (as it was perceived) was, at times, viewed as potentially dismissive of the work that still lay ahead for AIDS activists in South Africa. Overall, however, my relationship with TAC was an extremely valuable component of my fieldwork for all the reasons described above.

3.4.5. Key Informant Interview with 20 Policy Actors in Brazil and South Africa

Finally, I conducted 20 key informant interviews with policy makers, activists and academics in South Africa and Brazil in order to develop a deeper understanding of both policy processes and outcomes in each country tied to the political dimension of the research focus. For this aspect of my fieldwork, I used a snowball sampling method (Noy, 2008; Gravlee, 2011), where I worked with an initial and small group of respondents and asked them to advise me of other people whom I should also interview. In South Africa, I had a reasonable understanding of the policy terrain, and identified ten key respondents who were engaged as activists or academics in South Africa. These respondents were based in TAC, in TAC’s affiliate organisations (including MSF and Section 27), *uYaphi* and a media organisation (most of the women in the core group worked with these two organisation), artists who had worked with the BWG, and academics at the University of Cape Town. These interviews followed a structured format, as I aimed to understand, in particular, the current policy challenges that were emerging in South Africa, in the wake of the struggle for ARVs. I conducted these interviews in English, in the offices of each of the respondents. I obtained written consent prior to conducting these

interviews, and in addition to recording the interview, I also took notes; the notes and the interview were transcribed and later analysed in nVivo.

As discussed in Chapter One, the research I conducted in South Africa emerges from a long-standing research history that started in 2001 at the University of Cape Town (UCT). During this time I worked with TAC, developed research relationships with NGOs (including TAC's partners in the Community Media Trust and Section 27) and government officials (including the former Deputy Minister of Health). In contrast with South Africa, I was far less familiar with the geographic and political landscape of Brazil, and I was far more reliant on my colleagues in Recife to not only gauge the important policy debates currently taking place in the country, but also to navigate the space of Recife itself. The research I conducted in Brazil emerged from an academic collaboration with the Department of Social Development at the Universidade Federal de Pernambuco (UFPE). Starting in 2009 and continuing through the course of my PhD, I conducted research on gender and HIV in South Africa and shared this research through collaborative workshops and joint publications with a group of academics and activists in Brazil. The first phase of the research was published as a book in 2011; the second phase of research commenced in February 2011 and I visited Brazil then (and in 2010 and 2009) to discuss existing research data on HIV and health systems and to develop research methods for the next phase of research.

Recife is the capital of the north-eastern province of Pernambuco, and the fifth largest city in Brazil, with 1, 555, 039 inhabitants (measured in 2012).¹⁷ The north-eastern region of Brazil has recently witnessed an escalation in HIV-infection among women, compared to men (Okie, 2006c). Given the high prevalence of HIV among women in South Africa, also (problematically) termed the 'feminisation' of HIV (Harman, 2011), my Brazilian colleagues set up a research partnership with my former university to develop an exchange of ideas about addressing the gender-dynamics of HIV more effectively across the two countries. My fieldwork in Brazil was facilitated by this shared history of research, and supported in particular by Dr Ana Vieira and Dr Solange Rocha. Through these colleagues, I was introduced to a network of activists and activist organisations both within Recife, and across Brazil (including SOS Corpo and Abia AIDS, for instance). I was based in Recife for the duration of my fieldwork in Brazil, throughout August and September 2011.

¹⁷ [IBGE 2012 Census Population](#); accessed June 2013.

My interviews in Brazil were with key informants from the network of activist and academic organisations with whom I had worked in this research partnership; they include academics at UFPE and activists in feminist and HIV organisations in Sao Paulo and in Recife. I have anonymised these people and organisations at the request of the respondents. I cannot speak Portuguese. While this was part of the reason I did not opt to do a full length ethnographic study in Recife, I also wanted to find a way around this barrier as I had found through my previous collaboration with UFPE that there was much to learn from the network of activists and academics whom I had started to know, albeit tentatively and with much translation assistance from my colleagues. I therefore prepared interview questions in English, had them translated into Portuguese, and sent the written documents (including the translated consent form) to the respondents who had agreed to be interviewed electronically. This applied to seven of the ten key informants; I conducted three interviews in English. In all interviews in South Africa and Brazil, I asked the respondents to reflect on their role in each country's policy landscape; to discuss where they saw each country's socio-economic historic transformation and contemporary challenges; and to share their perceptions of each country's respective policy response to the provision of AIDS biomedicines in the public sector. My research in Brazil also moved over the edges of formal interviews and into what could also be described as 'hanging out'; I do not use the term 'ethnography' however, as this would give disproportionate weight to my fieldwork in Brazil compared to my fieldwork in South Africa. It was, however, these more subtle conversations, as I discuss in Chapter Nine, that really enabled me to understand the texture of the policy and embodied dynamics around AIDS biomedicine in Brazil.

I draw on the conjunction of key informant interviews and the ethnographic data I collected in 2010 and 2011 across each chapter of the thesis and centre on the key informant interviews in South Africa in Chapter Eight, and in South Africa and Brazil in Chapter Nine. These final two ethnographic chapters explore citizenship and governance as they are networked into South Africa and Brazil's constrained capacity (linked to global coalitions, funders like the Global Fund and economic blocs like BRICS) to provide and distribute AIDS biomedicine to HIV-positive citizens through their public health systems. Just as the methodologies enabled me to understand the two dimensions of the research focus, the chapters, too, reflect the relative 'ethnographic weight' of this multi-sited ethnography with the first four empirical chapters elaborating on the findings from the South African component of my fieldwork and the final chapter drawing the threads out to Brazil and the regional and global spaces that affect the governance of biomedical technology.

3.5. Reflexive Analysis

My field notes were a central component to my 'sense-making' during fieldwork, and in essence, functioned as a way to reflexively analyse my research as I moved through my ethnography. As I discuss above, it was through reflecting on the potential limitations of focusing solely on a group of women who had been AIDS activists that I introduced a further dimension to my research and conducted interviews with 40 men and women who were similarly on ARVs, but who had not been activists. My ethnography also spanned out to include participant observation by hanging out, and spending time with the families of the people with whom I worked, and engaging in the activist politics taking place in my fieldsite by joining the marches, pickets, press releases and protests that were taking place across Khayelitsha and in the Cape Town Metropole more broadly. In reflecting on my ethnography, and on the analysis held in the chapters that follow, I acknowledge that although my research was multi-faceted, and multi-sited, it was still ultimately grounded in the lives of the core group of women I worked most closely with.

The two research dimensions – the political and the embodied facets of AIDS biomedicine – intersected in the course of my fieldwork with each of the groups I worked with. Further, the conceptual framework outlined in the previous chapter calls for an understanding of the connections that draw these actors and actants into relationship with each other. Therefore, the findings I present in the following chapters locate this core group of women within a much larger assemblage that incorporates all of these research groups and methods, but ultimately, anchors them in the lives and bodies of the women in this core group. For the women with whom I worked, principally in the core group but also in the BWG, had engaged as powerful political actors and through these activist histories had been able to shape and navigate their lives in the particular ways that I detail in the following chapters. I do not, and could not, consider the political and embodied dynamics of access to AIDS biomedicines for the general population of HIV-positive people in South Africa as this was not the aim of my research.

I recognise, then, that the findings of this thesis apply to this particular network of research actors, and I do not claim that the argument I develop over the thesis pertains generally to all HIV-positive people living in South Africa, or even all HIV-positive people living in Khayelitsha. I do, however, suggest in Chapter Nine that the main argument I develop across this thesis, that biopolitical precarity is networked into the permeable body, may hold theoretical and political

relevance beyond this thesis, and that it may be worth exploring this argument in future work on gender, sexuality and citizenship, for example.

3.6. Ethics, Reflexivity and Positionality

As stated above, I secured Ethical Approval from the University of Sussex prior to commencing my fieldwork. In this section, I reflect on my positionality and the practical measures entailed in the ethical conduct of this research.

I was aware that, even with all the ethical permissions and procedures in place, my research could also be a process through which an ethnographic impression is taken; taken as photographs, videos and fieldnotes, taken away from these women, taken back to England's Brighton. The potential for this extractive research dynamic was recounted to me by the women I worked with, quite explicitly as a warning: I was told that they had given up on white people but because they trusted Nondumiso, who trusted me, they were giving me a chance to prove them wrong. My relationship with Nondumiso was also at stake: because I relied on her trust so fundamentally, I knew that I needed to make sure that I did not alienate the very people who were giving me this rare chance, and who all knew each other in the network of AIDS activists that I so strongly wished to know better.

The industry that has been built around HIV research is riddled with subtle and, perhaps less often, overt ethical contraventions. Having worked as a researcher in South Africa prior to commencing my PhD, I had become increasingly uncomfortable with 'HIV research' and my role in it. I had observed how quickly even the most 'human-centred and participatory' research could slip into obscuring the messiness of people's complex lives. This slippage happened, perhaps, in a quest to make research 'relevant' for policy by applying labels like 'HIV-positive', 'woman', 'Black', 'poor' in order to support development interventions aimed at precisely those people who – for all their complexity – struggled to live because these labels intersect so powerfully to generate precarity in South Africa. But the danger with this subtle dislocation of people's stories from their everyday lives lies in the perpetuation of a construction of the HIV-positive other. I attempted to address this risk of 'ethical slippage' in two ways.

First, I was rigorous in following the ethics procedures of consent, and of ensuring confidentiality and anonymity in my research relationships, as outlined above. This meant a constant discussion with the people with whom I worked about how and whether to use the accounts they shared with me during the course of my fieldwork, and also afterwards when writing this thesis. For instance, the group of women with whom I worked in the core and the BWG had been publically 'known' and visible as activists in court hearings, photographs and documentary films; our ethnographic work also drew very intimate details of their life into focus, and even though they had said that it was fine (for some it was preferable) that I name them in my thesis, I needed to check that this still applied for some of the stories they had shared with me. In most cases, we decided to use pseudonyms after all. I have therefore assigned pseudonyms to all of the people with whom I worked, unless explicitly asked to do otherwise, and I have removed identifying characteristics from my ethnographic accounts in the chapters that follow. The members of the BWG specifically requested to be named in my thesis, and it was with this understanding, that they gave me specific information that they were comfortable with me sharing (and where I was in doubt, as occurred twice in my interviews with this group, I did not include the account in my thesis).

Second, I integrated a series of visual methods into my research in part to understand people's lives and thoughts in a slightly different way to those afforded through participant observation. It was also important that the tools of these methods – the art materials used in creating the journey maps, and the cameras used to take photographs and films – belonged to the people I worked with and not to me. This was also clearly stated in the consent form, in which I signed that I would provide these materials and that if the women, at any point, did not want to continue working with me, that this would be fine and they would still own all these materials. I purchased cameras, SD cards, camera cases and batteries at the start of my relationship with each of the women; in doing this at the beginning, and not as a subsequent outcome, of our relationship, I trusted that if the women only wanted the tools and not a relationship with me, that they would not contact me again. When we discussed the films and photographs, I wrote detailed notes 'or photo-stories' about each image, and built up a composite understanding not only of the worlds of the women I worked with, but of the ways that they saw their world; the kinds of skies they found beautiful, the people they treasured, the rituals they knew I would never be able to see with my 'own eyes' and wanted to share with me. I have used very little of this material in the thesis. This is partly for ethical reasons; I did not feel comfortable using any images of people's faces, despite having clear permission to use the specific photographs the women shared with me. I have therefore used the visual

accounts sparingly, only when appropriate, where the identity of the people in the photographs is not revealed, and where I have obtained further permission to use them in this thesis.

With respect to my own positionality and the nature of this fieldwork, I acknowledge, in line with Whyte's (2009) caution about research on health and politics discussed above, that working with a particular group of people based narrowly on a health condition like HIV is also problematic not least given that I am white, middle-class, educated at a tertiary level and an HIV-negative woman. Not only was I all these labels – but I am a white South African, and I am not a heterosexual woman. My positionality contrasted starkly with those women with whom I sought to work, namely women who were HIV-positive, heterosexual and on ARVs. South Africa's history remains, as we see in this thesis, very present in all South Africans' lives, from the socio-spatial organization of race and class in Cape Town, to the chronic levels of unemployment among South Africans who are the same age as me, but who have not grown up with the historic (and contemporary) privileges conferred on white South Africans. I could understand why, in our first meetings, I was treated with a great deal of caution.

Instead of pretending that these labels did not exist, and pretending that I knew what I was doing in working with them, I tried another approach, which may or may not have been wise. I 'outed' some of the labels. In the initial meetings with the women in the core group, I said that I was not quite sure how best to secure their trust, or even sure how I was going to do this ethnography, and I asked for their advice in figuring this out. I also spoke of my own experiences of precarity. There were many days when I got very lost in Khayelitsha's maze of streets and could hear my voice reaching a hysterical pitch; because the women I worked with knew that I had been attacked in a neighbouring area during earlier fieldwork, they knew to point out that, at that moment, we were safe. This fear placed me very much in their hands: I was dependent on the women I worked with not only for engaging with me towards completing this PhD, but also for caring for me when I was lost, or anxious about my safety. This was embarrassing, too, because I could not pretend I was not often very afraid in the places that we hung out everyday, in the homes that they cherished, and in an area where they lived with persistent fear in ways I could not begin to fathom. In time, the labels became a tool for teasing. I was teased for the way I danced, the way I made tea, my poor attempts at speaking isiXhosa, the way I drank too much coffee, even the way my voice shook when we got lost in Khayelitsha.

This approach to ‘outing’ labels did not always work; and there were also many times when I was deeply uncomfortable with the disparities that marked such embodied differences in our lives. I did not, for instance, acknowledge that my partner was not a man, when so many of our conversations were about men, love and sex. This felt deeply disingenuous, but I did not know how to ‘out’ this particular label. I also heard a number of accounts of homophobia from some of the people I worked with. I was concerned, for instance, when a photograph was published in a local newspaper of me at a march against lesbian hate crimes; I was concerned that my colleagues with whom I had been working in activist organisations would refuse to work with me (they did in fact come up to me with the newspaper, shocked and I did not know how to respond). I was concerned, too, that in outing myself – even peripherally through the circulation of these public photographs – that I might place myself at risk in Khayelitsha, where the rape of lesbians was an extremely worrying trend during my fieldwork. Not only did I struggle with my own subjectivities in relation to the people and organisations with whom I worked, but I was also aware that my race and class inherited a privilege that no amount of ‘ethical research’ could erase. This was, perhaps, the most disconcerting aspect of my fieldwork, and my and my family’s history as white South Africans did also surface in numerous conversations in the year of my fieldwork (although not with any of the people I worked most closely with). These conversations, however, felt less daunting as my privileged subjectivities were ones I was more comfortable discussing than other subjectivities I embodied that, if ‘outed’, might place me, and perhaps the people I worked with, in danger.

3.7. Conclusion

This conclusion returns to Whyte’s (2009) call for comparative and multi-sited research on health and politics, particularly by ethnographers conducting research in the field of biopower and subjectivity, as I have done. Although this thesis emerges from fieldwork that traced connections linking actants and actors across multiple-sites, it is not a comparative ethnography. Instead, and still in line with Whyte’s critique of the biopower approach, I have attempted to illustrate some of the dialogues I observed between and beyond these fieldsites in order to create a differentiated picture to show,

[N]ot only the uneven seepage of science and medicine into social life, but also the uneven effects of different social conditions on the possibilities for the formation of health identities and subjectivities. With such ethnography in hand, we can begin to make comparisons over time and across social settings—still a major task for anthropology, medical and otherwise. (Whyte, 2009: n.p.)

I suggest that perhaps there is also value in Fassin's (2013) approach to 'layered ethnography' that seeks to look at sites through a slightly more critical lens, where multiple actors and spaces are considered as 'sites' in addition to particular locations historically viewed as a 'fieldsite'. It may therefore, not only be possible to develop a textured understanding of health and politics in a particular site by 'looking out' from it, but also by 'looking into' it more critically. My ethnographic methodology was anchored in a single space from which I looked out to see the myriad actors that tessellated with each other in an assemblage. I attempted to trace this assemblage through a methodology that engaged, too, with a range of actors across scale, within South Africa and also between Brazil, South Africa and the global arena. For this reason, I describe the approach I took to this ethnography as 'connective' rather than comparative. In sum, this is an ethnography anchored in women's lives, in Khayelitsha, but it also moves further into their bodies to understand how they embody HIV and AIDS biomedicines, and further out into the national, regional and global scale to trace the network of actors that assemble around the governance of AIDS biomedicines that are threaded back into their lives and their embodied vitality.

4. Pathways of Precarity

It's like when the skies fight, when the clouds are angry and dark. They crash into each other and lightning flies across the sky. You never know where the lightning is going to hit. That's what it's like with HIV (Zama, 2011).

The rain splattered across the windscreen as Zama and I drove along the slick highway to her office as an administrator and HIV treatment literacy facilitator. Zama is 33 years old and lives with her son, and sometimes her sister and her children, in a brick home in Khayelitsha. She acquired her home through the Reconstruction and Development Program (RDP) and views the stability of her home, its solid brick walls and robust gates, as a significant personal accomplishment. She also views her home, as indicated in a series of photographs she took in which she spoke to the state's presence and absence in her life, as an indication of the government's capacity to fulfil some of its constitutional obligations to her as a citizen in post-apartheid South Africa. Zama was diagnosed with HIV in 2001 and started treatment through the Médecins Sans Frontières (MSF) trial in Khayelitsha in 2002; this is part of the reason that, as discussed in the following chapters, Zama's view of the government is also tempered by her work with the Treatment Action Campaign (TAC) to call on the government to provide these medicines through the public health system.

By the time we arrived at Zama's office the temperature had dropped and neither of us wanted to stop our conversation. I turned the heating on and we sat together, twisted in our seats, talking as the rain collected and dropped down the windscreen. As Zama spoke about her younger self and the men she had had sex with without feeling that she could say no, without knowing how to say no, without believing she had the right to enjoy sex, I was struck by the clanging dissonance between what I thought I knew and how little I really understood. It was only at the end of my fieldwork in South Africa, after eight years of knowing each other, that Zama started to tell me how she had come to live with HIV; I first needed to see what Zama showed me before she would tell me what she actually meant.

One evening, a few months after our conversation about the skies that fight, Zama and I went to a hip-hop poetry performance entitled *Age is a Beautiful Phase* in honour of an anti-apartheid poet, James Matthews. Hanging out at the reception before the performance, we started chatting to Matthews's grandson. The conversation turned to the meeting place of

dreams and memories, of South Africa's history of dreamt possibility and our thoughts of its present. He asked us what we dreamt of becoming one day. Zama looked at him and said, "I am an artist. I am my dream". That evening was symbolic of continuities across age and across generations of struggles that span apartheid and post-apartheid South Africa. Matthews, frail with old age, spoke of his experience of forced detention and abuse, of the hands of the apartheid government that reached through the bodies of policemen in an attempt to quell his dissent. A young jazz singer put Matthews's poetry to music as break dancers contorted their bodies over and under each other across the floor to the rhythm of the poetry's beat. Matthew's poetry of South Africa's apartheid history was spliced with hip hop artists rapping about South Africa's post-apartheid struggles like gang violence, poverty and drug abuse. In the course of the evening, and precipitated by the conversation with Zama and Matthews's grandson, the title of the performance started to make sense: age can be a beautiful phase because it offers the possibility of actualisation. Zama's description of living her dream spoke to the realisation of hope: Zama was an artist. She was not first and foremost a woman living with HIV on ARVs. I had to see this before she would show me herself as a younger woman negotiating multiple and intersecting pathways of precarity.

This chapter explores the skies that fight, the proverbial lightning strikes that bring HIV into women's lives and bodies, through the theoretical lens of precarity and along three interlinked pathways. The principal source of precarity that emerged in my fieldwork relates to embodied vulnerability and centres specifically on women's and girls' bodies as corporeal sites of violence. In contrast with the other empirical chapters, this chapter centres on the core group of ten women with whom I conducted ethnographic fieldwork in South Africa. Epidemiological terminology, like 'routes of transmission', belies the complex actors and networks that make it possible for HIV to move into and become animate in people's bodies and lives; further, the narrative framing of HIV transmission along epidemiological 'routes' limits discursive expansion and locks policy responses for HIV prevention, treatment and care. Therefore, for practical and analytical purposes I use the term 'pathways' in dialogue with 'routes' and the concept of 'precarity' in dialogue with 'transmission'. This chapter delineates three 'pathways of precarity' that intersect and reinforce each other in order to highlight the interplay between HIV as epidemiology and HIV as a non-human actant (Latour, 2005), a 'thing with a social life' (Appadurai, 1988) that moves along social, economic, political and biological fissures, into and between people's bodies and lives. I argue in this chapter that precarity is borne through the body with HIV, as an actant, entering women's and girls' lives through relational networks that

travel (i) vertical pathways across generations, (ii) horizontal pathways between partners, and (iii) diagonal pathways among kin.

4.1. “So my baby gets HIV too”: Vertical Pathways of Precarity

Pregnancy followed by the birth, illness and potential death of a child were the metaphorical lightning strikes heralding HIV for the majority of the women with whom I conducted my fieldwork. This section details vertical pathways of precarity and centres on babies’ vulnerability to HIV through vertical transmission and the state’s historic failure to provide treatment to prevent mother-to-child transmission (PMTCT). This section also points to the pressures placed on women as carers for generations that come before and after them.

Without effective biomedical treatment to prevent vertical transmission, approximately one third of all HIV positive children die in the first year of their life, 50% in the second year, and 60% in the third year (Richter, 2009). In 1998 the HIVNET 012 Study concluded the efficacy and safety of single-dose nevirapine (NVP) and short-course zidovudine (AZT) for preventing HIV transmission from mothers to children (Guay, Musoke, Fleming, Bagenda, Allen, Nakabiito, Sherman, Bakaki, Ducar, Deseyve, Emel, Mirochnick, Fowler, Mofenson, Miotti, Dransfield, Bray, Mmiro and Jackson, 1999). In the same year, in South Africa, 70, 000 children were born with HIV (Richter, Stein, Cluver and Kadt, 2009). Despite the government’s initial commitment to establish the efficacy of nevirapine by conducting pilot studies in rural and urban sites, the then-President Mbeki undermined the policy response by claiming that AZT was toxic (Heywood, 2003). This stance was corroborated by the former Health Minister who similarly claimed that nevirapine was toxic (Geffen, 2005). The obstructive impact of these leaders’ equivocal stance on the provision PMTCT treatment is evinced, for example, in the government’s decision to deny an offer of a free five-year supply of nevirapine by the pharmaceutical manufacturer, Boehringer Ingelheim, in 2000 (Heywood, 2003: 285). In 2001 TAC took the Health Minister to court to compel her to authorise all public health facilities to provide nevirapine. TAC won the court case, which was then appealed, and on 5 July 2002 the Constitutional Court found that the South African constitution,

[R]equired the government to devise and implement within its available resources a comprehensive and co-ordinated programme to realise progressively the rights of

pregnant women and their newborn children to have access to health services to combat mother-to-child transmission of HIV.¹⁸

A second appeal by the state was denied and a national PMTCT program was finally initiated in 2003. However, as this section illustrates, the legacy of the government's AIDS denialism and failure to provide PMTCT treatment is a vertical pathway of precarity that women and their children continue to navigate in the present.

4.1.1. Lineages of Loss

Brenda was born in 1979 in the Eastern Cape and moved between this province and its adjacent neighbour, the Western Cape, throughout her life until she settled in 1997 to complete her high school education in the Eastern Cape. In 1999, in the course of her penultimate year at school, Brenda became pregnant. Her partner had told her that he was HIV-positive, but this disclosure held little meaning for Brenda because she did not know about HIV: "He was the first boyfriend. So we had sex without a condom. At that time I didn't understand HIV. That was 1999. So my boyfriend [told] me he was HIV positive, but like a joke". Brenda's geographic location in a rural village in the Eastern Cape placed her on the periphery of available HIV information and health services: "So I don't understand what he was talking about because I don't understand even HIV. I was in Eastern Cape, not here". The spatial correlation between Brenda's rural home and the absence of public health resources generated a further correlation: living on the periphery of public health services and information engendered Brenda's embodied precarity through her exposure to HIV. Without information about safe sex and without resources to prevent HIV transmission or pregnancy, Brenda contracted HIV, became pregnant and terminated high school prematurely. When recounting this period in her life, Brenda emphasised the layering of personal shocks: "It's the first time I sleep with a boyfriend, and then I get HIV and at the same time I get a baby". The spatial absence of the state in rural peripheries generated conditions of precarity through Brenda's inability to access public health resources like HIV-related information, condoms and treatment.

Without information about the routes that HIV travels, in this case through sex (without condoms) and through pregnancy, labour and delivery (without treatment), Brenda was unable to stop the virus from entering her or her child's body. Brenda's first child died

¹⁸ MTCT Court Case. The Treatment Action Campaign vs the Health Minister and 9 MECs of Health, 2001. <http://www.tac.org.za/documents/MTCTCourtCase/ConCourtMOHVsTAC.txt>; accessed June 2012.

because, “It was 1999 [and there was] no treatment. So my baby gets HIV too”. In 2001 Brenda became pregnant with her second child. During this time she also became very seriously ill. Hoping to access life-saving health care for her daughter and her daughter’s unborn child, Brenda’s mother brought her to Cape Town. In the absence of PMTCT treatment, Brenda’s second child, a girl, was born with HIV in 2001. She recalls spending the first few months of her child’s life in and out of hospital until she died in 2002.

In the same year that Brenda’s second child died, the South African government introduced single-dose nevirapine (sdNVP) to pregnant women. Brenda’s mother’s rationale for bring her daughter to Cape Town reflects an overarching finding from my fieldwork, namely the spatial distribution of public health resources in South Africa and its ramifications on the politics of life for people contracting and living with HIV. When compared to the rural peripheries, urban centres held a greater density of public health resources and therefore offered a greater possibility of life in terms of preventing horizontal and vertical transmission and sustaining life across generations through the provision of essential AIDS biomedicine. I discuss this in detail in Chapter Six. Historically, two factors differentiated the Western Cape from the Eastern Cape. First, MSF set up an ARV trial in Cape Town in 2001, three years before the government started to roll out ARVs through the public health sector. It was only in 2003 that MSF set up an ARV trial in Lusikisiki, a rural region in the Eastern Cape (Bedelu, Ford, Hilderbrand and Reuter, 2007). Second, the Western Cape contravened the national policy for mono-therapy by introducing dual-therapy treatment to pregnant women in 2004 (Youngleson, Nkurunziza, Jennings, Arendse, Mate and Barker, 2010). This provincial policy was informed by a Thai study that had confirmed that dual-therapy (nevirapine and zidovudine) was significantly more effective in preventing vertical transmission (Lallemant, Jourdain, Le Coeur, Mary, Ngo-Giang-Huong, Koetsawang, Kanshana, McIntosh and Thaineua, 2004).

TAC, through a series of court cases and civil disobedience campaigns, lambasted the government for its failure to provide essential PMTCT biomedicine and ARVs. Women, like Brenda, who had lost children because they had been unable to access PMTCT treatment joined TAC as activists and became central in TAC’s bid to compel the government to roll out PMTCT and ARV programs through the public sector.

Lilian, born in Johannesburg in 1972, spearheaded TAC’s campaign to compel the government to provide PMTCT; she testified on behalf of TAC and her affidavit was used as evidence in the court case. Over time, in 2012, Lilian created a journey map where she documented the



Figure 4.1. Lilian's Journey Map (Source: Lilian, 2011)

that reinforced each other: to combat apartheid's structural economic violence, her parents left her with strangers as they went to find work. Without any protection, Lilian was abused and raped by these strangers and then later, after running away from them, she was raped by relatives. She ran away again, and because she did not have any social or economic resources to draw on, she lived on the streets where she entered an abusive relationship and became pregnant in 1999. Like Brenda, her baby was extremely ill and she spent the first year of her child's life moving in and out of hospital with her until, in June 2000, her baby died. She learnt that she was positive when her child tested positive in 2000.

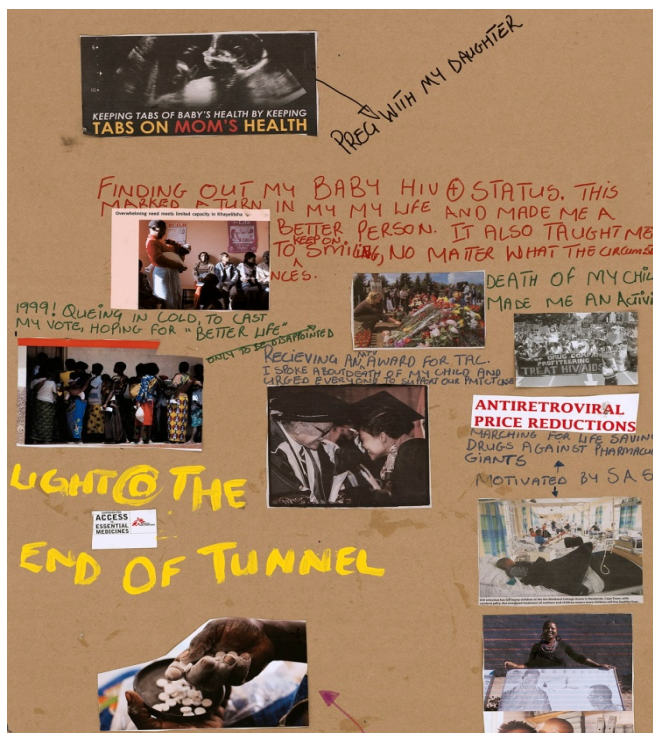


Figure 4.2. Lilian's Journey Map - Detail (Source: Lilian, 2011)

journey of her life. Starting forty years earlier, in 1972, Lilian notes her birth on the top left hand side of the map. Next to this date, she writes of the abuse she endured throughout her childhood because she did not have the protection of her parents. This aspect of Lilian's life, described in the section below, generated conditions of embodied precarity

After testing positive, and as a result of losing her child, Lilian joined TAC as an activist. This story is documented on the right hand side of her journey map, in contrast to and in dialogue with the narrative on the left of the map documenting her embodied vulnerability to rape and abuse in the years leading up to her daughter's birth. The full map is pictured above left, and the detail from the right hand side of the map is pictured left.

On the top right hand side of Lilian's journey map is a photograph of a

pregnancy scan, a foetus in profile, pictured in black and white, and underneath is the phrase “Keeping tabs of baby’s health by keeping tabs on mom’s health”. Next to the image she writes, “Preg with my daughter”. The three photographs below this top image are tiered and mirror the progression of her life into activism.

The first photograph is of a waiting room in a clinic in Khayelitsha with a woman holding her child. The second photograph is of a grave strewn with flowers. Next to this photograph she has written “Death of my child made me an activist”. She has drawn an arrow connecting this photograph with a third photograph of people lining up in a queue. Next to it she has written “1999. Queing [sic] in cold, to cast my vote, hoping for ‘better life’” and along the arrow to the photograph of the grave representing her dead daughter, she has written “only to be disappointed”. Lilian’s experience of losing her daughter “marked a turn in my life”; it prompted her to join TAC and to start antiretroviral therapy. In bright yellow paint she has written “Light at the end of the tunnel”; the words circle around a small piece of paper with the MSF logo promoting the Campaign for Access to Essential Medicines. This visual account of Lilian’s life conveys the journey she travelled from losing her daughter into becoming an activist; as Lilian writes, “death of my child made me an activist”.

This points to Lilian’s belief that the democratic state is intimately entwined with her and her child’s capacity to live; the ‘politics of life’ are iterated by Lilian’s conviction that the state should ameliorate precarity by creating conditions for a ‘better life’, for her child to live without HIV and for herself to live with HIV on ARVs, by providing essential biomedicine through the public health system. Her rationale for becoming an activist, therefore, was to challenge the way the democratic state was creating conditions of vulnerability through its failure to provide treatment to prevent vertical transmission. Lilian now has a young boy who, she says, is ‘living proof’ of her work as an activist to compel the government to provide PMTCT treatment. Similarly, in 2006, two years after the Western Cape started providing dual-therapy PMTCT treatment, Brenda was able to access the treatment she needed to prevent HIV from being transmitted vertically to her child.

The pathways that enabled HIV to move into Brenda and Lilian’s bodies, and into their children’s bodies, illustrate the biopolitical nature of precarity in two ways. First, in Brenda’s case, she was placed at ‘heightened risk of exposure to disease’ through the failure of the public health system to reach rural areas with essential public health resources (like HIV information, condoms and biomedicine). Second, the state generated ‘politically induced

conditions of precarity' through its failure to provide treatment to prevent vertical transmission from Brenda and Lillian to their children, and through its failure to provide essential AIDS treatment through the public health system when they became ill.

4.1.2. Generations of Life

In 2011 Brenda was pregnant with her fourth child. I follow the narrative of her pregnancy and her child's birth in this and the following sections in order to illustrate the ways in which the pathways of precarity intersect with and shape each other.

In Brenda's maternity hospital the long queue of pregnant women was apparently best served by solid lines of hardwood benches that stretched down a corridor which doubled-up as a waiting area. The individual blue chairs were reserved for the smaller number of women seeking specialist care in doctors' offices just off the main corridor. I was Brenda's birth-partner and we were at the hospital for her final check-up before her due date in May. I waited on the bench as Brenda moved in and out of rooms along the corridor for various check-ups. Sitting next to the only man in the waiting area, he told me that his partner was having a boy; he first referred to her as his wife and then looked me in the eye and said, "Actually, she's not my wife yet but I hope she will be". His partner came out of her appointment a few minutes later and he left with her, not a word spoken between them, but his hand touched hers briefly as they moved towards the exit. Brenda came and sat down on the bench in the spot that had just been vacated by the man when he left with his partner. Her feet were swollen and her turquoise dress was stretched across her stomach. When I met Brenda a few months earlier this dress had hung loosely on her body. We sat on the bench as I read through the paperwork Brenda had given me about my responsibilities as her birth partner. I read and signed two sets of documents and handed them back to her. "No, this one is for you Beth," she said in her soft deep voice as she handed back one set of forms. I took the forms thankfully and kept them in my bag to buttress my flailing confidence until her son, Mpilo, was born six weeks later. I return to Brenda's pregnancy and Mpilo's birth in the section below.

Miriam, like Brenda, was born in 1979 in the Eastern Cape. Like Brenda, Miriam too moved to the Western Cape to access biomedical treatment. In Miriam's case, however, her move to the Western Cape was prompted by her daughter's failing health and not by her own ill-health. Miriam was compelled to stop high school three months before her final examinations to take

care of her mother. When she returned to her mother's home, she entered her first sexual relationship and, like Brenda, became pregnant through her first sexual relationship in 1997. Unaware of how HIV is transmitted and unable to access PMTCT treatment, Miriam was unable to protect herself or prevent her daughter, Nena, from contracting HIV.

Nena was born as Miriam's mother died. Miriam wrote rather than spoke the stories of her younger self in the pages of a diary that moved like an unspoken conversation between her bag into mine. Sometimes she would refer to statements from her diary, but never to the stories in their entirety. I understood not to refer to them but to know them intimately so that I could 'get' Miriam's oblique references to them as mutual affirmations of trust. In her diary Miriam wrote about shutting down her mother's home after she gave birth so that she could live in the hospital between the wards that held her mother and her daughter - holding them in beds but not restoring their ill bodies to health. She wrote of her heart-break at choosing between her mother's death and her daughter's life and her discomfort with her decision to leave her mother, knowing she would never see her again, and take her daughter out of the frail failing clinic in heart of the Eastern Cape to the medical hub of urban Cape Town. Miriam's partner encouraged her to bring their daughter to his city because it held promise of medicine that would decipher her child's illness and potentially save her life. Miriam left her mother and moved to Cape Town where her daughter was given excellent, albeit belated, medical care. Nena's illness was deciphered in 1998; Miriam learnt of her own HIV-status when she learnt that her daughter was HIV-positive. She and her partner then both tested HIV-positive, but her partner refused to believe his status and therefore refused to join support groups and access the same MSF trial that enabled Miriam to commence ARVs when she became eligible in June 2001. Nena's father died in 2006.

One day, when leaving the clinic after Miriam's monthly ARV check-up, Miriam pointed back at the clinic and said, "Cape Town's my home because it gave life to my child... I don't even want to tell you how small she was when we got here. But I want to die in the Eastern Cape because it is the home of my ancestors". Nena has lived with HIV for twelve years, and is currently on second line ARV treatment. As a result of her delayed treatment at the onset of her life, Nena struggles with severe cognitive disabilities. HIV destroys neuronal tissue in the central nervous system, causing developmental delay or dysfunction in HIV-positive children's motor, mental and emotional development (Abubakar, Van Baar, Van de Vijver, Holding and Newton, 2008). Miriam has struggled for seven years to move her daughter into a school that would meet her needs; it was only at the beginning of 2012 that the government was able to assign Nena to a

school for children with learning impairments. Zama's nephew, like Nena, was born in the Eastern Cape in 1997. He, too, was born on the cusp of death, abandoned by his father because the actual cost of his care outweighed, in his father's mind, the potential of his son's life. Unlike Nena, he did not survive by being moved to an urban 'medical hub' like Cape Town; he survived because a doctor in the Eastern Cape paid privately for him to access AIDS biomedicine. His delayed treatment, however, resulted in both physical and cognitive impairments. The ill-health that characterised the beginning of these children's lives fundamentally constrains their current and future health and wellbeing. In line with Fassin's work on embodied memory (2007), these children bear witness to the persistence of embodied precarity as a result of delayed treatment and the legacy of poor health care in rural South Africa.

In this section vertical pathways span epidemiological routes, as HIV moves from mothers to babies, and social pathways, as seen in the shifting biopolitical relationship between women and the state around access to health resources, and particularly PMTCT treatment. The generation of children born in the 'window period' between escalating rates of HIV transmission and the provision of ARVs and PMTCT serve as a visceral memory of the government's absence and of the political and profoundly personal struggles that ensued for HIV-positive women as they negotiated the precarity of their own and their children's lives. Further, they illustrate the vertical transmission of precarity as their mothers were unable to access health resources to enable them to prevent HIV from entering their own or their children's bodies.

4.2. "It's hard to be a girl in this country": Horizontal Pathways of Precarity

Like a Polaroid image that becomes defined with time and light, the proliferation of rape and abuse of the women I worked with and of the generations of girls that stretched before and after them moved into sharp relief over the course of my fieldwork. This reflects a broader context in which HIV has become discursively welded to gender-based violence. The words go hand in hand with statistics that shock and numb; that are so real they become unreal and people become numbers. In a cross-sectional study in three South African districts in the Eastern Cape and Kwa-Zulu Natal, researchers interviewed 1738 men aged 18 – 49 years (Jewkes, Sikweyiya, Morrell and Dunkle, 2009). This study found that 27.6% of all men had

raped a woman or girl; rape of a current or ex-partner was reported by 14.3% of the men; 11.7% had raped an acquaintance or stranger (but not a partner) and 9.7% had raped both strangers and partners. Of all the men who were interviewed, almost half (42.4%) had been physically violent to an intimate partner (Jewkes *et al.*, 2009). Longitudinal Analysis of a cluster-randomised control trial undertaken in the Eastern Cape between 2002 and 2006 with 1099 women aged 15 – 26 years indicated, conclusively, that there was a causal relationship between relationship power inequity and intimate partner violence and an increased risk of HIV infection among young South African women (Jewkes, Dunkle, Nduna and Shai, 2010).

Through this section I aim to make the numbers enumerated above more human and, further, to challenge the hegemonic and ubiquitous development discourse that positions poor Black women as ‘vulnerable’ without recognising the nuanced albeit fraught strategies that women employ to navigate precarity. The horizontal pathways articulated in this section span epidemiological routes of transmission between individuals through unsafe or coercive sex and rape, and social pathways of precarity, like gender inequality, that contribute to horizontal transmission. The intersection of these epidemiological and social pathways are widely theorised in South Africa, both reflecting and fuelling national and international categorisations of Black, poor women as ‘vulnerable populations’ susceptible to HIV infection. These intersections did emerge in my ethnography and are discussed below. However, in line with de Certeau’s (1984) notion of ‘making do’ and as discussed in greater detail in the following chapter, women simultaneously embodied, resisted and performed precarity in complex configurations that challenged linear assumptions of women as either ‘deserving subjects’ or as ‘autonomous agents’ (Cornwall, Harrison and Whitehead, 2007; Jones, 2011b, a).

4.2.1. An Epidemic of Rape

Having completed her general check-ups in the various rooms that led off the maternity hospital’s main corridor, Brenda’s last stop was the HIV-specialist doctor. We moved across to sit on the blue chairs closer to the doctor’s office in a smaller waiting area on the other side of the corridor. A piece of pink paper hung like a speech bubble from the ceiling outside the doctor’s office; a cheerful backdrop to the ‘HIV’ that was handwritten in large black letters. The connection between the HIV speech bubble, the consulting room and the people sitting in the smaller waiting room was tacit but present. The architects or hospital planners had perhaps considered stigma when they created an even smaller waiting area – effectively a line

of chairs sandwiched between two walls – where people could wait without being seen by those passing through or sitting in the main corridor. Brenda was open about her HIV status: having sufficient legroom was the main consideration in choosing where to sit.

Brenda's body ached and she moved around in her chair trying to get comfortable as she waited to see the 'HIV doctor'. She brought her camera out of her bag, and we slunk down in our chairs, our legs stretched out into the more private space of this waiting area. We sat for about ten minutes watching a film that she had made with her friend in her partner's home in Kuyasa. Brenda chopped vegetables and washed dishes as she spoke about her life to her friend, how she had come to contract HIV and the impact that HIV had had on her life since 1999. After watching the film, Brenda took me through the photographs she had taken since we had last seen each other. She stopped at a photograph and adjusted her body to look at me looking at the photograph. It was a picture of her grandmother, her face lined with age, sitting on a bench in the sun outside her home. She looked sternly at the camera with each arm stretched around the small shoulders of her two great-granddaughters. The girls looked blankly at the camera, both in frayed dresses with grazed knees, unsmiling, seeing but not seeing Brenda behind the camera.

Brenda touched the camera's screen, tracing the faces of her relatives. "Beth, do you remember that school teacher?" She spoke with a tone of urgency; a tone that asked me to hear the underlying implications of what she was saying. I moved up in my chair and looked at her. "You know, the one who's been in Vukani [a weekly local newspaper distributed in Khayelitsha]? The one who raped 30 children in Khayelitsha," she said. "He raped these two girls". I put my hand on her hand on the screen still showing her grandmother and nieces, generations that came before and after her; we sat in silence, shoulders touching. Later, Brenda was called into the doctor's office. It was a quick consultation and she came out saying "It's a boy, Beth". Travelling back to Khayelitsha, she said, "I'm glad it's a boy. It's hard to be a girl in this country... But Beth! I really wanted a girl".

As a young girl the same age as Brenda's nieces, Lilian's parents left her to live with strangers. As described above, the precarious decades of life leading up to her daughter's death are documented along the left-hand side of Lilian's journey map. In the top left hand corner, next to a photograph of a piece of coal in the shape of a light bulb, she writes that she was born in Johannesburg, a coal mining hub, in 1972. Above a photograph of a group of young girls in school uniforms, she writes "1979 – Started School" and under this "1979 – 1980 – Endured

abuse". Next to the dual commencement of school and abuse, she has pasted an excerpt from a magazine article which says, "I've been through hell and survived. You can too!" In blue paint, and in large letters, she writes, "Tired of abuse, left and all alone in the streets". Under this statement are two photographs, one that she has taken herself and one cut from a magazine. The magazine photograph is of a hunched woman walking alone on a wet dirt road under a bleak bleached white sky. Lilian's own photograph sits alongside this image and is of a homeless person in a sleeping bag lying on top of folded cardboard boxes next to a dustbin. She explained to me that she took this photograph because it reminded her of her life as a young woman before she joined TAC. A third photograph in the quadrant of the map that displays her childhood depicts three men, of different generations, with their arms around each other. Under this, in red pen, she writes, "Raped by a family friend – 1982". Lilian's experience of abuse, the topographies of precarity recounted through her journey map, wound along a pathway that took her into an abusive relationship where she became pregnant. Without access to PMTCT treatment, these horizontal pathways of precarity shifted into a vertical route of HIV transmission, and she gave birth to an HIV-positive child who, like Brenda's and Miriam's children, started life on the cusp of death.

4.2.2. Eschewing Shweshwe: Navigating Risk and Pleasure

In my sitting room I had a bright red shweshwe-patterned bowl made by Miriam. It held condoms, femidoms and lubricant received from an LGBTQ organisation for free and so they were covered with rainbows and statements like "celebrating sexual diversity" or "homophobia is un-African". Knowing about femidoms and condoms, the women in the core group were most interested in the lubricant. They did not want to 'encourage' their partners with intimations of desire, but they said that they often experienced a great deal of pain through sex. The women oscillated between wanting the lubricant and not wanting the messages on the packaging. I left it at that, but later realised that all the sachets had been removed from the bowl. An unspoken agreement ensued: I kept the bowl stocked with lubricant and the women kept taking the sachets. Weeks later, Miriam told me that she thought lubricant was an excellent invention.

This vignette speaks to a broader tension that emerged in my fieldwork: women enjoyed intimacy and sex, on the one hand, but found it difficult to negotiate the actual conditions of sex with their partners on the other hand. Three conditions, in particular, contributed to horizontal pathways of precarity linked to embodied risk through women's sexual relationships

with men. First, the majority of the women in the core group felt unable to insist on safe sex with their partner. Second, they found it difficult to negotiate the frequency of sex. Third, they struggled to balance their desire for intimacy and support from their partner with the knowledge that their partners had other sexual relationships. These conditions congealed into pathways of embodied precarity: through unsafe sex with partners who had unprotected sex with multiple partners, the women risked contracting new strains of HIV and developing viral resistance to their ARVs.

A few months into my fieldwork, Lilian told me that she had found out that her partner was having sex with other women. She laughed, saying that he was “a catch” and that his infidelity was not sufficient reason for her to end their relationship. However, Lilian struggled to reconcile her love for her partner with his infidelity. By the end of my fieldwork, Lilian had become angry. Unwilling to negotiate her partner’s infidelity any longer, she ended their relationship. Miriam’s partner, too, had multiple sexual relationships. She had learnt that her partner, Samkelo, was having sex with multiple other partners by reading the text messages on his phone. When Miriam confronted him the first time, he said that she was his only partner and that the last time he tested (in 2005) he was negative; he repeated this to her each time she challenged him about his infidelity until Miriam decided to stop asking and simply work on the understanding that he was lying, and that he was having sex with other people. Samkelo did not believe that he needed to test again and felt that he, and not Miriam, was at risk when having unprotected sex because Miriam had been open about her HIV-positive status. With this rationale, he refused to wear condoms. This generated great concern for Miriam because she felt compelled to have sex with him in order to keep him in her and her children’s lives, but was concerned about contracting other viral strains and developing resistance to her ARVs.

Her concern for her health extended to her commitment to parent her daughter, Nena: “I have my daughter to look after Beth. At least my son has his father. But my daughter only has me. I have to take care of myself for her”. Her son, Khanyo, stays with Samkelo – his father - in Kuyasa because he attends the school across the road from Samkelo’s home. Miriam chose to keep Khanyo in this school as a strategic measure to compel Samkelo to take parental responsibility for their son. These measures also distributed the financial responsibility of Miriam’s children across two households, and enabled Miriam to maintain her economic independence and to negotiate the frequency of her contact with Samkelo.

I first learnt about Samkelo on Miriam's birthday in January 2011. We went up on Table Mountain where we could look out over the peninsula. Standing on the mountain Miriam traced the vein of the N2 highway out of the city to Khayelitsha and said, "It's hard to see beauty when you're down there. Sometimes you can't even see the sky". Later, Miriam took me through the photographs that she had recently taken. She showed me a photograph of a friend's skirt and pointed out the fabric. It was a fine pattern of white lines on a blue background. This pattern, called Shweshwe, indicates that wearer is married. A long conversation ensued as Miriam told me that she would never get married because, "Men are macho when they get married. If I got married the xhosa tradition would kill me". I asked Miriam if she believed that traditions could change, and she said yes, "As women we can live our own lives better now compared to our mothers. But marriage will never change. That's why you'll never see me wearing shweshwe. I will never get married". By opting out of marriage, Miriam was able to insist on living in her own home with Nena and by remaining in a sexual relationship with Samkelo, she ensured that her son's father stayed in his child's life and shared responsibility for her children as a co-parent.

Miriam's beliefs around marriage and 'macho men' were also expressed by Yvonne who refused to marry her partner because it would entail "submitting to his family", to his mother, and to isiXhosa traditions and expectations of women. Yvonne was born in 1982 in Johannesburg, and moved to Cape Town with her mother and stepfather, both of whom were strongly involved in the anti-apartheid movement. Their involvement would later shape her decision to become an activist with the TAC, as discussed in the following chapter. Yvonne worked with Zama as an HIV treatment literacy trainer and lives with her young son and mother in a peri-urban area neighbouring Khayelitsha. She eschewed marriage, saying that isiXhosa traditions would 'trap her'. According to Yvonne, isiXhosa marriage traditions entail: solely wearing skirts; wearing a headscarf; never wearing trousers; not talking back or up to her husband; only spending time with other married women; and never saying no to sex. Over December 2010 Yvonne went to her family's home in the Eastern Cape and spent time with her partner and his family as they celebrated his brother's circumcision. She said that she was treated as his wife, even though she was not married to him, and that she was glad to return to Cape Town where – in contrast to her time in the Eastern Cape - there was accessible water, functional electricity and where women did not need to do all the work or take care of all the men. Yvonne maintained intimacy with her partner, but established and exerted her physical, social and economic autonomy by refusing to get married, by living in her own home with her mother and her son, and by sustaining her financial independence.

These narratives indicate a confluence of factors that engender vulnerability, particularly for young women, alongside strategies that women draw on to navigate intimacy and pleasure and complicate the picture painted by studies showing linear causality between gender-inequality and HIV. Eight of the ten women in the core group lived in a separate home away from their partner. Earning their own income and living in their own home, or with their parents, were central strategies for the women to negotiate their desire for intimacy and partnership alongside their concerns about the risks that intimacy entailed for their bodies and their lives. Brenda, however, lived with her partner, and therefore employed different strategies for negotiating the embodied implications of his insistence on unprotected sex. After her final hospital check up, we navigated our way back to the home where Brenda lived. As we drove past the 'Three thousands', the metal shacks the size of a small room that cost R3,000, Brenda said that this would be her last child. Her partner was HIV-positive, and did not want to use condoms when having sex; she felt unable to insist on using condoms because she was living in his home and not in her own recently purchased 'Three thousand'. She had not finished paying it off and needed to rent it out to her cousins so in order to pay the final instalments. Her tactical response to the difficulties entailed in owing money, in negotiating sex, and in preventing pregnancy, was tubal ligation.

Brenda checked into hospital at the end of May 2011 with contractions; she was ready to give birth. We waited over two days, chatting and napping on gurneys in the corridor, for the long line of emergency caesareans to abate. Brenda was taken into the operating theatre and once she was prepared for surgery, I was brought in and positioned on a chair next to her head. She lay with her arms stretched out and held down, drips going in and clips sending measurements out to the blinking board monitoring heart rates and blood pressures. Just as the doctors told her that they were starting the caesarean, she said, "Tie". The doctor checked with her that she meant that she wanted her 'tubes tied', and she said, "Yes". A clipboard with the consent form was brought to her right hand, still tied to the table, to sign. She signed, and the doctors proceeded with the caesarean. Brenda lay still behind a blue sheet constructed a few centimetres away from her chin. The doctors, sensitive to her possible sense of disconnection, spoke sparingly but considerately to her through the surgery. Finally they said that her son was ready to come out, and that she would feel some pressure up against her ribs. Brenda's eyes filled with tears. Her son was born, immediately bundled up and taken to a scale by one of the doctors to be weighed. Brenda looked at me and, echoing the statement she made the previous month, whispered, "It's so hard to be a woman". Mpilo was brought around the

operating table so that Brenda could see him. I held him while Brenda, still crying, spoke to him; on the other side of the blue sheet the doctors tied her tubes and stitched her womb closed. Brenda's decision to have her tubes tied was one way for her to navigate the pressures placed on her by her partner's insistence on unsafe sex; she was not, however, able to protect herself from contracting other strains of HIV, and this placed her at higher risk for developing resistance to her ARVs.

This section illustrates the dynamic interplay of gender and HIV based on the lives of the women who formed the core of my ethnographic fieldwork. Deviating from structuralist approaches that permeate analyses of South Africa's 'gender and HIV' nexus, I suggest that women's lives are not dialectically shaped by structures that enable, enact and sustain violence (Farmer, 1996, 1998) or by women's agency as they 'act up', also described as 'globalisation from below' (Robins, 2005). Instead, women embody precarity while strategically and simultaneously performing and resisting assumptions of precarity. In the following chapter I argue that the performance of embodied precarity was a tool for exposing and resisting violence, for finding a language through which women could lay claim to rights and resources in the context of embodied vulnerability linked to gender and HIV.

4.3. "I am the household": Diagonal Pathways of Precarity

The third pathway transects vertical and horizontal modes of transmission and explores diagonal pathways of precarity that include structural inequalities as they are manifested in high rates of unemployment, substance abuse and implicit economic pressures placed on women as primary care-workers in households. These structural inequalities, specifically linked to poverty and unemployment, bear witness to the legacy of South Africa's history and emerged throughout my fieldwork, particularly in the photo-stories, as main sources of discontent with South Africa's current government. The findings from the photo-stories, films and interviews in which people 'spoke to the state' are discussed in detail in chapter seven. This section seeks to foreground women's affective relationships with kin. It departs from the epidemiological framing of 'vertical' or 'horizontal' transmission routes by placing emphasis on the relational dynamics of precarity that both women and men navigate in households and kinship-networks. I consider, in particular, a series of structural factors that put strain on these relationships.

The linked dynamics of poverty and unemployment were the significant factors that impinged on women's relationships with their kin. Financial insecurity, in particular, was a persistent form of precarity that both men and women struggled to negotiate in the context of high levels of unemployment and poor levels of education (Mlatsheni and Leibbrandt, 2011; Rankin and Roberts, 2011). South Africa's unemployment rate among those aged 15 – 65 years is 25.5%, as measured in the first quarter of 2012 (Statistics South Africa, 2012).¹⁹ Unemployment for young people is significantly high; almost half of those in the labour force cohort aged 15 – 24 years were found to be unemployed (Rankin and Roberts, 2011). The long term impacts of youth unemployment have been referred to as 'scarring' (Scarpetta, Sonnet and Manfredi, 2010) as a result of systematic social exclusion (Jordan, 1996) linked to the multidimensional consequences of long term unemployment (Sen, Environment and Development, 2000). The notion of scarring is pertinent for this third pathway as it raises the embodied consequences of structural inequality evinced, for example, in the relationship between unemployment and harmful practices like drug use and alcoholism, as experienced by both men and women.

The partners, brothers and sons of the women in the core group moved back and forth between unemployment and informal employment; this economic volatility prompted some men to rely on women for material support. In turn, this placed pressure on women to stretch their meagre earnings to accommodate their kin and also placed women at risk when they refused to share their earnings or other material resources with their kin. Economic volatility also prompted some of the women's kin to resort to crime as an economic survival mechanism; this placed men, as criminal actors, in positions of vulnerability alongside the vulnerability their acts entailed for those who experienced the crime. Crime was also linked to alcoholism and drug use, although the causality was not clear. In some instances, alcohol and drug use precipitated crime and in other cases the women noted that drug use and alcoholism were ubiquitous among young men in the Cape Flats, and therefore ancillary to the less frequent criminal acts.

4.3.1. Negotiating Affect and Harm

Sibongile was born in 1986, and lives with her uncle and her two sons in Guguletu. "I am the household," she told me as she explained her uncle's alcoholism, and the relentless demands – "Boys eat so much!" – of being a mother to two boys and like a mother to her uncle. Sibongile

¹⁹ <http://www.statssa.gov.za/publications/statsdownload.asp?PPN=P0211&SCH=5222>, accessed May 2012.

was thirteen when she had her first son. She shared this story with me as we walked down the road together, both of us looking ahead, trying to pick our way through the traffic,

“My family were really disappointed in me at first. I was to blame after all [for getting pregnant]. But then they supported me; my grandmother especially supported me. My mother is schizophrenic, so I’ve never been able to rely on her. My grandmother was there for my boys. But she died last year, and then I got into a very dark place. I’m trying to come out of it now” (Sibongile, 2011).

Sibongile lived with her children in the home that her grandmother had secured as part of the post-apartheid reparations process. This home, however, is owned by her uncle, her grandmother’s son, and she feels unable to negotiate ‘household matters’ with him because, “He has the power. I must just do everything. Buy the food, cook, clean. He just drinks his money”. Sibongile was deeply frustrated by her uncle’s alcoholism and his financial dependence; the income she derived from her work with *UYaphi*’s Income Generation program was difficult to predict and this further entrenched her dependence on living with her uncle, and catering to his financial demands, because she was unable to afford her own home.

Thandiswa, like Sibongile, earned a meagre income through her work with *UYaphi*. Unlike Sibongile, she lives in her own home. It was awarded to her after many years of negotiating the complex Reconstruction and Development housing process. Thandiswa was born in 1969, and she has two children, Lindisizwe (27 years old) and Babalwa (14 years old). She lives in her home with her two children, her sister and her sister’s two children, and her brother. All of the members of her household are financially dependent on Thandiswa. Therefore, in order to supplement her meagre income from *UYaphi*, Thandiswa buys frozen chickens wholesale in Bellville, a suburb northeast of her home in Tsakana Location; she then cuts the chickens into

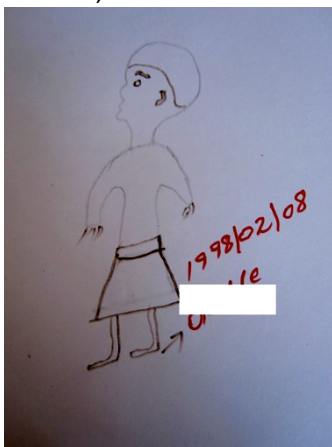


Figure 4.3. A social map drawing of Babalwa (Source: Thandiswa, 2011)

their constitutive parts, breasts, thighs and so on, and bundles different parts together in ‘chicken packs’ and sells them to people in her neighbourhood. Thandiswa is an artist like Zama, and like her son Lindisizwe. When I asked her about her family, she picked up a sheet of paper and a brown pen, put them on her lap and drew each of her family members as she told me about them. Thandiswa drew herself in the middle of the sheet, with her son and daughter drawn on either side of her, their profiles facing Thandiswa. Babalwa is drawn wearing a skirt (left), with raised eyebrows and round eyes that look like question marks.

Babalwa, in fact, looks very similar to this painted image. Her face and her demeanour are inquisitive. She excels at school and when I asked her what she wanted to do when she was older, she said, “I want to be a doctor. I want to help people.” Thandiswa’s principal objective in earning money through selling chicken pieces and sometimes repairing clothes is to make sure that Babalwa can finish high school with all the resources she needs in order to be able to attend university. Her ambition for her daughter is foiled, frequently, by the cost of her son’s heroin addiction.

In order to pay for heroin, Lindisizwe had stolen everything of value in Thandiswa’s home aside from the items of furniture that were too heavy to remove. He had done this on multiple occasions over the period of his addiction – five years – and Thandiswa lives in anticipation of returning from work to a barren home. In the course of my fieldwork, Thandiswa often sat with me, crying with despair at her son’s drug addiction. She spoke of her son and of his addiction separately; she was extremely loving towards her son but very angry with his addiction. One day we decided to go up to Signal Hill with her daughter for a walk. Thandiswa showed us various medicinal plants and told us about their healing properties. We sat together on the grass looking out over towards Robben Island and, as I rubbed the leaves of an *imphepho* plant between my fingers, she told me too about her son’s recent decision to enter a rehabilitation centre.²⁰ Her sense of relief was palpable. Later, Thandiswa pulled out a plastic envelope that held about ten A4 sheets with different drawings on them. Her son, she said, wanted to be a designer. Using coloured felt tip pens, Lindisizwe had crafted funky shoes, long elegant dresses, waist high pencil skirts and business shirts. Those drawings were an indication of the possibility of another life for Thandiswa’s son as a designer and not a drug addict. Months later, at the end of my fieldwork, on the day that we went to see the photograph that Gideon Mendel had taken of her and Babalwa at the TAC offices, she told me that her son was taking heroin again. He had left the rehabilitation program and engineered a way to redeem the deposit that she had put down with an adult education program for a course he agreed to take in computer literacy.

Drug use and alcoholism impacted the lives of the women in the core group directly and indirectly. In Sibongile’s case, her uncle’s alcoholism undermined his capacity to seek employment; or perhaps employment had not been possible, and this ‘scar’ had manifested through alcoholism. Sibongile’s uncle’s alcoholism, and his unemployment, in turn placed

²⁰ *Imphepho*, or *Helichrysum*, is known to have powerful healing properties and is frequently used by *sangomas* in South Africa.

financial pressure on Sibongile to 'be the household' and wash, cook, clean and pay for all the household costs. The impact of substance abuse was directly felt by Thandiswa as she lost all the items of value in her house to her son's addiction. In Miriam's case, both she and her home were physically threatened as a result of her brother's drug addiction. The dents in the front door of her home bear witness to her brother's previous attacks and to his latent capacity to hurt Miriam if she challenged his dependence on her. It was therefore in her best interest, on multiple levels, for her brother to be earning an income even if it was through illegal activities, like running the shebeen over the road from her home.

In the middle of a night during my fieldwork I woke up to the sound of a text message. Miriam wrote saying that Khumbuzile was drunk and threatening to burn down her house. Khumbuzile had asked Miriam for money, and had insisted on staying in her home because he could no longer stay in the shebeen. His aggression alerted Miriam to possibility of a repeated attack on her home, but she felt unable to negotiate rationally with him because he was high on a drug called Tik (crystal methamphetamine). He had been addicted to Tik for months, and Miriam had slowly withdrawn from having any contact with him as she watched him lose weight and become more deeply entwined in his work, and possible criminal activity, with his friends in the shebeen. He had asked Miriam for money because he had been arrested by the police a week earlier for selling alcohol illegally in the shebeen. Miriam was angry with the police for arresting her brother, saying, "It's not fair. He is trying to earn money so that he doesn't need to rely on me so much, and now the police are even taking that away." She was angry, too, because she would be placed in a position of capitulating to her brother's financial dependence or resisting his requests and facing the threat of his violence.

I called her that night, but she did not answer the phone. When I reached her the next morning, I learnt that she had taken her daughter and moved across to stay in Samkelo's home. In seeking shelter from her brother, she had to concede to Samkelo's insistence on sex. Miriam was extremely angry with her brother for placing her home at risk, and for forcing her to move in with Samkelo. A few days later, however, Miriam had worked out a plan. A distant relative had died in the Eastern Cape and she offered to buy her brothers a bus ticket to travel back to his funeral. They agreed, but she only bought one-way tickets for each of them. Two weeks later we stood in the long queue outside the Checkers moneymarket counter where Miriam only transferred money to her younger brother, Alungile, for his return ticket. In this way, Miriam managed to resolve this issue by effectively consigning Khumbuzile to the Eastern Cape without money to return to Cape Town.

4.4. Conclusion

In this chapter I considered HIV as the primary non-human actant that moves through a series of pathways into women and children's bodies. In doing so, I sought to extend epidemiological frameworks that frame the movement of HIV along horizontal routes into women's bodies, or along vertical routes into babies' bodies. Across each section in this chapter, we see how HIV came to enter women's bodies and lives along these pathways and we see too, at each junction, how women navigated these precarious dynamics: by moving across the country to access life-saving medical care for their children; by joining TAC and working as activists to compel the government to provide ARVs through the health system; and by maintaining financial independence and separate households in order to be in a position to negotiate sexual relationships. My ethnography, therefore, challenges the discursive construction of HIV-positive women as passive victims; however, I recognise that I worked with a particular group of HIV-positive women who accessed socio-economic resources and were also strongly politicised through their anti-apartheid and AIDS activism. Although these findings cannot be generalised, they point to a more nuanced set of gender dynamics that I introduced in this chapter and reflect on across my thesis, namely women's constrained agency to act on and through a network of actors that are implicated in their embodied precarity. This chapter and the next focus on two primary actants within this network, namely HIV and AIDS biomedicine, as they draw attention not only to their intra-action with(in) women's bodies but also to a broader set of socio-economic dynamics that enables these actants to enter and become animate in women's lives.

The proliferation of sexual violence in the accounts that emerged during my fieldwork reflected a larger backdrop in which HIV transmission is linked to gender inequality in South Africa. HIV was able to move into women's bodies through unprotected sex because, as Brenda explained, she was not aware that she needed to protect herself from the virus; or as Zama told me, she did not feel that she was able to negotiate the frequency or kind of sex that she had as a young woman. While the presence of gender inequality, and its brutal manifestation as sexual violence in girls' and women's lives, was a strong feature of my fieldwork, I was still confronted by the explanatory limitations of epidemiological assertions that stipulated a correlation between gender inequality and higher rates of HIV infection

among women compared to men. I do not dispute this correlation; in fact, part of the rationale underpinning my research lay in the multiple and intersecting inequalities that seemed to drive HIV, in epidemiological terms, into women's lives and bodies. This was most striking when, in 2008, young women in South Africa were almost four times as likely to be HIV-positive compared to young men of the same age (20 – 24) (Dorrington *et al.*, 2006; Johnson *et al.*, 2013). Overall prevalence in this age group has subsequently declined, but the characteristics of prevalence according to sex remained the same: young women are still more likely to be HIV-positive than men (UNAIDS, 2012).

In trying to make sense of these figures from the outside looking in, and before starting my fieldwork, I came across studies that linked these statistics to sexual violence (Wood and Jewkes, 1998; Speizer, Pettifor, Cummings, MacPhail, Kleinschmidt and Rees, 2009; Jewkes *et al.*, 2010; Jewkes, Sikweyiya, Morrell and Dunkle, 2011). Articles with titles like "AIDS has a woman's face" (Annan, 2003) or "Troubling the angels" (Lather and Smithies, 1997) proliferated in studies that explored this correlation. Other research suggested that sexual violence and its relationship to HIV occurs against an inflected backdrop of pervasive and entangled inequalities in South Africa, where gender, sexuality, race and class powerfully intersect to reinforce poor Black women's vulnerability (Dworkin, Colvin, Hatcher and Peacock, 2012; Jewkes and Morrell, 2012). The trope of 'transactional sex' perhaps best characterises the accounts of HIV and intersectional inequality. These studies suggest that (particularly young) poor Black women are less able to negotiate sex, or in some cases, that women actively engage in sex with wealthier men in exchange for material goods. This has been observed in South Africa (Leclerc-Madlala, 2003; Dunkle, Jewkes, Nduna, Jama, Levin, Sikweyiya and Koss, 2007), but also further up the continent, in inland fisheries for example (Béné and Merten, 2008), where life and livelihoods are, like most places in the world, relational and navigated materially through affect and intimacy.

Although these studies give texture to the correlation between gender inequality and high rates of HIV incidence among women compared to men, they also seem to support a paradigm that has fuelled development interventions to 'empower' women by foregrounding women's relative lack of power compared to men. Women appeared to be subject not only to men's brutality but also to the effacement of academic research that blames men and strips women of their relative agency. Cornwall has similarly argued that by analytically positioning men as perpetrators, we not only fail to see how men too navigate fraught social and economic landscapes alongside women (1997; 2004; 2007), but we also fail to see the strategies women

draw on in their active strategies to navigate their everyday lives. This is illustrated, for instance, in Cornwall's (2002b) ethnography in Ado-Odo, Southwestern Nigeria, as she observed how intimacy, money and love are negotiated by women in their intimate relationships, defying constructions of women as passive sexual subjects who do not, or cannot, exert agency and insist, like men, on satisfying sex and mutual affect.

Ethnographic research from elsewhere in Africa has also started to challenge the blunt correlates implicit in transactional sex analyses (see Wamoyi, Wight, Plummer, Mshana and Ross, 2010; Wamoyi, Fenwick, Urassa, Zaba and Stones, 2011). More recently, ethnographic research in Sierra Leone has shown how relationships are formed around the flows of fish and love in a tightly stretched maritime economy: fishermen and bandawomen (women who dry and sell the fish harvested by fishermen) both resent and rely on the affective ties of obligation and care that draw them into relationship with each other (Diggins, 2013).

In my fieldwork, it was Zama's account of the skies that fight, of the pathways she travelled in her life, that brought the complex realities of women's lives 'to life' and prompted a shift in my sense-making of the HIV-gender dyad in South Africa. As we see in this chapter, although HIV entered women's bodies and lives along horizontal, vertical and diagonal pathways, women also worked strategically to manage their precarity. Yvonne, for example, insisted on living in her own home, away from her partner, in order to be in a position to negotiate sex. Miriam, too, stayed in her own home as a way to manage her sexual relationship with her child's father. We see, too, how women negotiated their material wellbeing strategically through their sexual relationships, as Miriam placed her son in his father's care by keeping him registered at the school just over the road from his father's home.

Further, if HIV generated precarity as it entered and became animate in the body, then it is also analytically important to understand how it came to take on this life in women's bodies. In this respect, my research connected with and also challenged prevailing accounts of the gender-HIV dyad. Simply ascribing HIV transmission, in epidemiological terms, to entrenched gender inequality does not, in itself, engage with the complex pathways that women navigate between desire and risk in their sexual relationships, and in extremely difficult socio-economic contexts. In this respect, my ethnography found that women are subtly, and sometimes with great difficulty, negotiating their intimate relationships with men by forming separate households and by working and establishing their financial independence. This was not a straightforward matter of asserting agency or submitting to intersecting structures of

inequality; here my research challenges structural theories that position agency in relation to structure (see Giddens, 1990) without looking at 'grey space' in between.

For, we see that although Brenda enjoyed her sexual relationship with her partner, she felt unable to insist on using a condom when having sex because she was reliant on her partner for her home. If we consider her decision to have her 'tubes tied' in light of this picture, it seems that Brenda's life fits the 'gender-HIV' narrative of the economically dependent woman struggling to negotiate sex in an unequal relationship. We could also interpret her relationship as transactional: providing sex in exchange for a home. But we would be wrong. By looking at the multiple pathways that HIV travelled into women's bodies, we do not only see the socio-economic structures that "make it hard to be a girl in this country". We also see the myriad tactics that women employ along these pathways to seek medical care for their children, to secure their financial independence, and to negotiate the risks and desires that surface in sexual relationships. Brenda's decision to have her 'tubes tied' was a tactical one, just as her decision to stay in her partner's home was a conscious, if not difficult, choice; she was not financially dependent on her partner, and she made these difficult decisions on the basis that she had recently bought her own shack, and was financially navigating the repayment of her home by renting it to her cousin while she stayed in the home of her boyfriend. Therefore, as we see with Brenda, although it was not always possible to fully negotiate sexual relationships, this dynamic cannot simply be ascribed to gender-inequality or explanations held in transactional sex analyses; it requires a more fine-grained understanding of biopolitics and precarity.

Where precarity surfaces in sexual relationships, it has embodied implications for women and men's wellbeing: through unprotected sex, HIV, as an actant, becomes more adept at mutating and resisting ARVs when moving, through horizontal pathways of blood and semen, between partners' bodies. The ability of HIV to mutate and become resistant to ARVs underlines the importance of developing and distributing new AIDS biomedicines that can continue to block the life cycle of this particular actant. Women, as I discuss in the following chapters, not only exert their constrained agency in their social and sexual relationships, but also very much in their political relationship with the state through various shifting citizen practices around AIDS biomedicine. Lilian, for example, describes how her child's death marked her decision to join TAC and fight for her own and other HIV-positive people's lives. These nuanced dynamics connect to but also problematise the 'gender-HIV' dyad in which gender-inequality is one of the main 'drivers' of the HIV epidemic in South Africa (Dunkle and Jewkes, 2007; Dunkle *et al.*,

2007; Jewkes *et al.*, 2010; Q, 2010). I suggest that the gender-HIV dyad is problematic not only because it positions women as passive victims of men who are, conversely, held to be active perpetrators or ‘vectors of transmission’. More fundamentally, it is problematic because these discourses direct our attention towards individuals or ‘cultures of inequality’ and away from the biopolitics of structural violence in which the state is implicated.

Not only does the state enter the body of individuals or populations through disciplining techniques (Foucault, 2008) but we see how its absence, too, exerts an effect on the body. For Miriam, the state was absent in the Eastern Cape, as it was in many of the women’s lives, in so much as it did not provide essential AIDS therapies that would have blocked HIV from moving into her daughter’s body, that would have stopped her daughter from starting life on the cusp of death. The absence of the state was visible too, in the responsibility that was conferred to women, implicitly, to provide unpaid care for kin who could not access health care in rural parts of the country, or who could not access essential medicines that would sustain their lives even when health centres were accessible and functional. Bearing Agamben (1998) and Arendt (1958) in mind, it is not simply that the state is absent, but rather that the state – through its absence – refuses to engage with citizens. Butler (2004) describes this ‘refusal to engage’ in light of Levinas’s (1979) philosophy of the face in which the other’s precarity becomes visible only when we look; if the state does not look, then it does not see the precarity that it induces. In refusing to acknowledge the emergence of HIV in South Africa and the vital importance of providing PMTCT, the state refused to acknowledge the biopolitical population of HIV-positive pregnant women; I suggest, therefore, that the expectations of care placed on women, and the limited life of their children born in this ‘window period’ bear witness to Agamben’s figure of homo sacer: “Bare life is thus paradoxically made part of the political by the very fact of its exclusion” (2007: 206).

I conclude this chapter by proposing that the failure of the state to address the conditions that enabled HIV to move along these three intersecting pathways is illustrative of two strands of biopolitical precarity; each strand speaks to the relative presence and absence of the state as it is embodied as precarity in people’s lives. First, the absence of the state was visible in the failure of the education and employment sectors to address the socio-economic inequalities of apartheid’s racist education system, which continues to have ramifications for generations of Black South Africans who are disproportionately affected by unemployment and intransigent poverty. This is evident, in particular, in the diagonal pathways of precarity in which structural violence is felt in the ‘scarring’ of unemployment for most of the men who were related to the

women with whom I worked; it is not clear whether Sibongile's uncle's alcoholism was a result or a cause of his inability to work. Nor is it clear that Lindisizwe, Thandiswa's son, was more prone to drug addiction because he could not find work. But these inter-related dependencies speak to a despondency I observed among the men I came to know, albeit more peripherally. A despondency that, in turn, translated into Khumbuzile's decision to work in a shebeen and on the shadowy edges of criminality in order to earn a living. Without access to a fair and equal education as they were growing up during apartheid, these men struggled to earn a living as adults; the women I worked with, on the other hand, were placed under enormous strain to care for the members of their stretched households. The absence of the state in these systems in turn placed women at "heightened risk of disease, poverty, starvation, displacement, and of exposure to violence without protection" (Butler, 2004: 2). Miriam, for example, was threatened with physical violence by her brother, Khumbuzile, when she attempted to assert her independence – and drew his attention to his own relatively limited capacity to earn money.

The second biopolitical strand of precarity relates less to the absence of the state evinced in failing social and economic systems and more about the active presence of the state in creating politically induced conditions of vulnerability "for populations exposed to arbitrary state violence and to other forms of aggression that are not enacted by states and against which states do not offer adequate protection" (Butler, 2004: 2). This strand connects to vertical and horizontal pathways of precarity. Women's ability to stop HIV from entering their own bodies was very much connected to their constrained and fluctuating agency in their sexual relationships. This, as discussed above, is connected to a broader set of intersecting inequalities, like the gendered expectations around care that forced Miriam to terminate her education and start caring for her brothers and her mother; evinced, too, as Zama entered her first sexual relationships, like Miriam and Brenda, without knowing how to insist on using condoms and, at times, without feeling it was possible to say no. The historic failure of the state to provide treatment to stop HIV from travelling along vertical pathways from mothers into their children's bodies generated further sources of precarity. Lilian describes how, like Miriam, her child's illness was indecipherable, and that her child's death was directly attributable to the state's refusal to provide PTMCT to HIV-positive pregnant women. Further, I explore in the following chapter, once ARVs were introduced then the biopolitical presence of the state came to be felt in the embodied memory of pre-ARV illness, the persistent ill-health of HIV-positive children, side effects of treatments and the failure of the state to introduce

third line treatment to those who were failing the second (and therefore final) treatment regimen.

I suggest that these three interlinked pathways are, one, a function of the first biopolitical strand of precarity, namely the failure of social and economic systems to mitigate against women's and girls' corporeal exposure to violence. Two, the pathways speak to men's and women's embodied memory of historical and contemporary structural violence, exacted by the government, in line with the second biopolitical strand of precarity. Finally, women's tactical negotiation of structural violence within each pathway opens a discursive space for resisting epidemiological and social constructions of vulnerability as women navigate their affective and inter-personal relationships. These actions take place in the space between the current conceptualisations of structural violence as 'top-down' or resistance as 'globalisation from below'.

5. New Generation Struggles

The previous chapter focused on HIV and three epidemiological and social ‘pathways of precarity’ that enabled the virus to move into women’s bodies and become animated through their lives. In doing so, it highlighted the biopolitical dynamics of precarity linked to vertical transmission, horizontal transmission and diagonal networks of kinship and affect. Mirroring the previous chapter’s conception of HIV as an actant that replicates and engenders vulnerability in the body, this chapter introduces AIDS biomedicine as an actant that halts, for a time, the progression of HIV to AIDS.

Across this chapter, I explore iterations of biopolitical precarity and performativity in relation to the struggles encountered by the people with whom I worked, at different stages and in different spaces of their lives. In the previous chapter, I approached HIV from an oblique angle; instead of looking at HIV incidence solely as an indicator of women’s socio-economic and biological susceptibility to infection, I discussed how – in each pathway – women worked to secure their vitality as they, too, struggled with their own and their children’s embodied precarity linked to and extending beyond the manifestation of HIV in their bodies. In this chapter, I move from exploring the biopolitical pathways along which HIV travels into women’s bodies to understanding how ARVs are differently embodied and experienced in their lives. The importance of thinking about biomedicine through a social lens, as it is held and embodied differentially, follows a long history of medical anthropological research. Rayna Rapp’s ethnography, for example, on diagnostic technologies and amniocentesis emphasises the importance of looking beyond narrow framings of biomedicine as a ‘programme’, located in a clinic space and de-centered from people’s everyday lives. She describes a ‘bio-techno-sociality’ that emerges between knowledge formed within the families she worked with, and biomedical and technicist discourses:

[O]ur understandings of new biomedical technologies are significantly enhanced when we examine them in a wide social framework and do not confine our investigation to the clinic. This broader perspective enables us to see technologies in play, as they are understood, appropriated and occasionally resisted by the parties who deploy them (Rapp, 2000: 205).

With Rapp’s approach to understanding new biomedical technologies in their social context, and as Marsland (2012) notes, the starting point of this ethnography matters: the shifting

biopolitical landscape in South Africa, and globally, means that my research found that ARVs can no longer be framed as a 'technology of life' (Rose, 2006), and as the 'technofix' to the problem of HIV and potential death (Lock and Nguyen, 2010). These dynamics with and in the body prompt a rethinking, then, of sociality as subjectivities shift across time and in different spaces (Whyte, 2009). Across this chapter I explore the intra-action of HIV and ARVs with(in) the body and describe how these actants generate different forms of risk and opportunity as they are embodied over time. I propose that, in understanding HIV and ARVs as non-human actants that travel complex pathways into and within women's bodies, we can also start to view some of the more nuanced dynamics that women negotiate in their everyday lives, through their relationships, and beyond categorisations that frame HIV infection as a problem, a proxy for women's vulnerability, with ARVs cast as the solution.

Two linked sets of narratives around the embodiment of these actants emerged in my fieldwork, and they draw the focus out from the body to situate the body in relation to South Africa's shifting biopolitical landscape. The first set of narratives articulate how people perceive the intra-action of HIV and ARVs in their sustained vitality. The second set of narratives articulates the complex embodiment of vitality alongside precarity. These narratives flow into each other and do not represent a totalising view of the effects of HIV and ARVs in the lives of the people with whom I worked; the positive effects of ARVs (as unequivocally essential for sustaining life) were implicit and the precarious vitality of the people with whom I worked was fundamental. However, I discuss this set of narratives here because I found, in the course of my fieldwork, that a related and emergent set of struggles was becoming salient: speaking to the narratives of embodiment described above, they complicated the view that ARVs are a 'technofix' and present a challenge to the idea that only 'local biologies' like HIV and ARVs are embodied. These emergent struggles were biopolitical, and they related first to the intra-action of HIV and ARVs 'within' the body; and second, to the 'outside' socio-economic context in which people's bodies were situated. I describe these emergent concerns as 'new generation struggles'.

The first section traces the life-cycle of HIV and ARVs as actants in relation to the biomedical framing of TAC's treatment literacy programme in which many of the women had worked whilst in TAC. Thereafter, the second section considers the 'social lives' of these actants as they were articulated in the narratives of embodied vitality, related to this history of activism. The third section outlines the narratives of embodied precarity. Reflecting the dual character of these 'new generation struggles', this section details the shape of these struggles in relation

to, first, the precarious intra-activity of HIV and ARVs, and second, to the context in which ‘lives are lived’ and the fraught dynamics of (un)employment and economic (in)security. Whilst this chapter introduces these ‘new generation struggles’ as they are embodied, Chapter Seven looks across the two research dimensions and outlines how these embodied struggles are political and have precipitated a corresponding set of citizen practices.

5.1. The Social Lives of HIV and ARVs

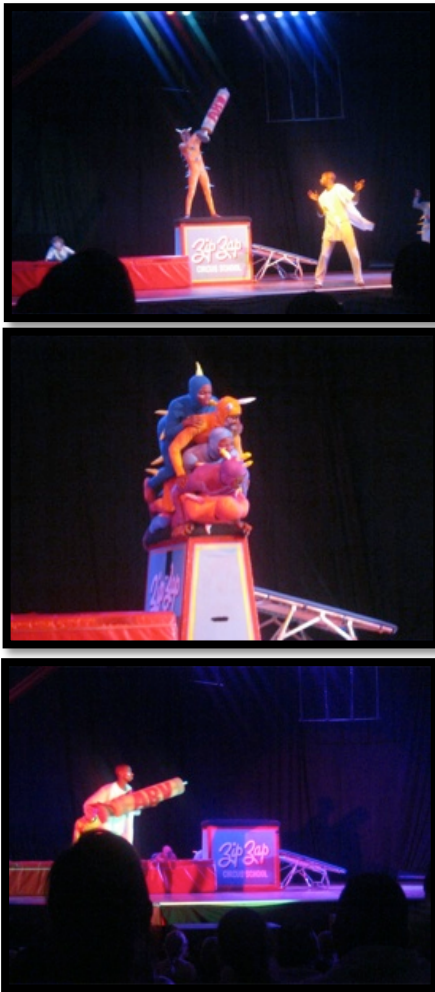


Figure 5.1. A photo-story of HIV and ARVs in action at the Zip Zap Circus (Source: Mills, 2011)

The adjacent photographs were taken at a circus show that I went to with the group of women I worked with, and their children and other young people also living in their homes. In the performance, Yandisa’s son, Siyalela, came on stage as a doctor wielding a large syringe that represented ARVs. An act ensued as children ran around the stage dressed up as the HI virus, fooling the doctor, hurling the ARVs over trampolines and flying over each other in an attempt to stay alive and outwit the hapless ARV-wielding doctor. Finally, the life of the virus was cut short when a brave and brazen little boy simply went up to the ‘virus actors’ and play-punched them in the face. This (admittedly confusing) performance of ARVs and virus actors on a stage, speaks to the approach this chapter takes to explore the ‘social lives’ of HIV and ARVs as non-human actants with and in the arena of the body.

This circus visit had been keenly anticipated, largely because Siyalela had been practising this scene for weeks before the circus show ‘went live’; he lived with

the other performers in Obs, a few houses away from *uYaphi*. As you may recall, *uYaphi* is the income generation programme that Yandisa and the other women visited at least once a week to drop off the bowls they had made, to collect their new orders and to buy the sheets of designer paper and tubs of glue that they needed to complete the next week’s work. A friend of mine who worked at the circus had been telling me, too, about this household of young

people and the playful tricks that travelled between their work place in the circus tent in Cape Town and their home in Obs. A week before we went to see the performance, Yandisa expressed, over a meal of chicken and tea at *uYaphi*, what she thought about this particular act, saying, “Youth these days!” Everyone muttered in consent, as though we knew what she was talking about. I was not quite sure myself, but I thought it might have to do with young people not taking significant things, like HIV or sex, as seriously as they should. I wondered if Yandisa thought that running around in a circus (although at that stage I could not quite picture it) dressed up as the HI virus was undermining the severity of the HIV-related TB infection that, in 2004, had stripped her body of all its reserves and prompted her to go back home to her mother in the Eastern Cape because she believed she was going to die. I was wrong, though. Yandisa went on to say, “It’s good, you know, that they are talking about these things. Like, well. About HIV. Because, it’s a part of our life now: this virus, these drugs.”

Yandisa, and all the women sitting around the table having lunch, had been actively involved in TAC’s campaign to destigmatise HIV and to compel the government to bring ARVs into the country. The women who did not work with *uYaphi* – Zama, Lilian, Sindiswa and Yvonne – had also worked as treatment literacy practitioners (TLPs), and were all at that time working in HIV-education programmes. The accounts I discuss below are therefore grounded in TAC’s treatment literacy programme, which communicated the science of HIV and ARVs to South Africans in order to equip people with information to place pressure on their doctors, local government representatives and on the national government to bring ARVs into the country. What was significant in my research was the way that this scientific knowledge was internalised and complicated by the women’s experiences of the effects of both HIV and ARVs as they intra-acted with each other, in their bodies over time. For this reason, I discuss, in the same technical terms used in TAC’s treatment literacy programme, the life cycle of HIV and ARVs to locate the ethnographic accounts that I present in the following sections, and in order to explain what I mean when I refer to the intra-action of these actants with and in the body.

Latour’s (2005) conception of actants is potent (although not by any means universally appropriate) for understanding how the smallest things – like viruses and medicines – that we categorise as non-human hold agency in ways that other approaches (in structuration theory, or even the theory of practice) only attribute to humans. The previous chapter explored the dynamics that enabled HIV to enter women’s bodies and lives. Once in their bodies, the virus itself enters a life cycle. In the first stage of its life in the body, the virus attaches itself to the receptor and co-receptor on the surface of a CD4 cell. This stage, colloquially called ‘Binding

and Fusion', is compared to a key entering a lock: once HIV is bound to the receptors, it can fuse with the CD4 cell and release its genetic material into the cell. Reverse transcription, or the second stage, is enabled by an enzyme (called reverse transcriptase) in which the virus's genetic material is changed and integrated into the host DNA. Thereafter, the virus is able to 'con' the cell with its new genetic material and it enters the cell's nucleus at which stage it can then integrate itself into the body's own genetic material. Here it may 'hide' or remain dormant, or it may become active. Once activated, the virus uses the body's enzymes to create more specialized genetic material that form longer proteins. In the next stage, called Assembly, the virus uses the body's protease enzymes to cut the longer proteins into individual smaller proteins, thus replicating itself as a new virus. The final stage echoes its name, Budding, as the virus pushes itself - like a bud - out of its host CD4 cell, taking part of the cell's membrane; this membrane covers the virus and contains the structures needed for the newly replicated virus to be able to attach itself to a new CD4 cell and begin the process again.

There are several classes of AIDS medicines that act on the virus at these different stages of its lifecycle. Entry inhibitors, for instance, act in the first stage and prevent HIV from binding to the CD4 cell receptors and fusing with the CD4 cell; there are only two of these drugs – maraviroc and enfuvirtide. They are highly expensive and currently not available in South Africa's public sector; they are, however, available in Brazil. As their names depict, nucleoside reverse transcriptase inhibitors (NRTI) and nucleotide reverse transcriptase inhibitors (NtRTI) block HIV at the second stage of its lifecycle; NRTIs are described in medical terms as 'chain terminators', and in my fieldwork, they were described by the women I worked with as 'nukes' – both highly metaphoric terms that I discuss below. Stavudine (d4T), one of the ARVs that emerged as most problematic for its negative effects on people's bodies, falls into this class of drugs. Non-nucleoside reverse transcriptase inhibitors (NNRTI) were described by the women as 'non-nukes'; NNRTI's cause 'molecular arthritis' by disabling the enzyme that the virus uses to replicate itself. There are two generations of medicines in this category: the first generation medicines are described as 'less flexible', with HIV more likely to resist the work it does in the body. The second generation medicines have 'a more flexible structure' and can resist mutation more effectively. These medicines include nevirapine and efavirenz; both ARVs are used in South Africa's public health system. Integrase and maturation inhibitors intra-act with the virus in the final two stages of its life-cycle. Raltegravir is an integrase inhibitor that is also classed as a third line ARV; it is currently available in South Africa's private health sector and in Brazil's public sector. As I discuss in Chapter Nine, due to the governance of the development of AIDS medical technologies, particularly linked to patent laws governed by Trade Related

Intellectual Property Rights (TRIPS) regulations, it is prohibitively expensive and unless South Africa changes its national patent legislation to make use of TRIPS flexibilities, it will not be available to people when HIV outwits their second line medicines.

I discuss the life cycle of HIV and the corresponding ARV medicines here for two reasons as they relate to the following two sections and to the shifts in biopolitical precarity and biosociality over the decade following the introduction of ARVs through MSF in Khayelitsha. First, the dynamic properties of the virus illustrate the value of conceptualising HIV as a nonhuman actant with agency, a 'thing' that interacts with and becomes a part of the body through its life cycle (Latour, 2005). Second, ARVs have been specifically designed to engage with HIV at different stages in its life, and thus point to the value of conceptualising both HIV and ARVs as actants in relationship with each other and with(in) women's bodies. The term 'intra-action' is pertinent here because, as Barad (2007) explains, it more accurately denotes entanglement of things – in this case, bodies, viruses and medicines - that have previously been constructed as bounded and distinct. The movement of HIV into CD4 cells, by actively transforming its RNA into the CD4 cell's DNA, points to the agency of the virus and the profound entanglement of the virus with the body, right down to the structure of the DNA. It also points to the embodied value of the struggle for ARVs, as activists engaged with the government and with international actors (like pharmaceutical companies) to bring these medicines into the country's health system, and into their bodies. The following section discusses the narratives of embodied vitality linked to ARVs among a group of activists in the Bambanani Women's group who had engaged in this historic struggle, and represented the effects of both HIV and ARVs as actants in their bodies through a series of body maps. In this respect, this chapter moves on from the previous chapter's consideration of precarity that enables HIV to enter bodies to explore how people tactically manage this precarity by 'acting up' through activist organisations in order to bring ARVs into the public health system, and into their bodies.

5.2. Amandla! Awethu!': The Struggle for ARVs and Embodied Vitality

On 3 June 2011 Khayelitsha resonated with vuvuzelas, drum majorettes and song as hundreds of people, many wearing HIV-positive t-shirts, marched through the streets linking the Ubuntu Clinic in Site B with the OR Tambo Stadium. A few weeks earlier Miriam and I had sat in the sun on the pavement outside the TAC and MSF offices in Khayelitsha as a photographer took

photographs of ten people against a brick wall in the crowded parking lot. There was a great deal of hilarity as we stumbled down the staircase trying to get chairs out into the parking lot, as people pulled faces at the camera, sang, tried on and swapped HIV-positive t-shirts and spoke of "how far we've come since those dark days". The photographs were collated and printed as a banner that was carried by the marchers through Khayelitsha and placed in the front of the OR Tambo stadium on 3 June, the day that marked a decade since MSF had first started providing ARVs in South Africa. The photographs were of people who, like Miriam and Thobani, had been part of the first cohort of people to start ARVs through this trail-blazing trial in 2001.

Walking from the march into the OR Tambo Stadium, we were met by large banners saying "Early treatment for HIV-positive infants saves lives. Treat the children!", "Take control. Take an HIV Test!" and "STOP TB". The posters called for ongoing activism and indicated a shift from accessing essential medicines to a focus on introducing new medical technologies, saying "Save Lives. Transform TB prevention, diagnostics and treatment". Miriam, Thandiswa, Brenda and I were handed t-shirts that had been made for the day, saying "20, 000 HIV-positive on treatment. Khayelitsha 2001 - 2011". Body maps made by the Bambanani Group in 2003 hung from the first floor of the auditorium over the heads of people as they entered the ground floor. School children were seated in stalls that circumscribed the first floor, each school singing songs in competition with the others. It was a festival for ARVs, a celebration of life and an affirmation of collaboration between activist coalitions and local and provincial government.

The spatial configuration of political alliances and of biosocial groupings was visible in the organisation of chairs - who sat where and next to whom - in the auditorium. White chairs for 'VIPS' - those on ARVs - lined the periphery of the stage on the ground floor. The chairs on the left hand side were for the first cohort of HIV-positive people who started ARVs, and the chairs on the right were for the speakers and representatives from local and provincial government, MSF and TAC. Miriam, Thandiswa and Brenda went to sit on the left of the stage; Miriam was later called out, and I saw her then processing down the aisle of the auditorium with the other ten people who had been photographed and a larger group of activists, ululating, singing and dancing. They moved down to the open area in front of the stage and formed a circle, still dancing and singing. The MC for the opening ceremony came into the centre of the group shouting, "Amandla" [Power!]. Everyone in the stadium stood up and we shouted: "Awethu!" [To us/the people]. Acknowledging the legacy of the struggle for ARVs, the MC recited a series

of names of people who had died. At one point she shouted, "Long live the spirit of Christopher Moraka, Long Live!" Moraka had died of treatable oral thrush because he could not afford to pay for the cost of fluconazole under Pfizer's patent and the government refused to provide this treatment through the public health system. People bearing witness to the legacy of activists like Moraka, those who had been able to access essential medicines, fanned out from the central circle to sit on the white chairs to the left of the stage, followed by the keynote speakers who moved to the chairs on the right of the stage. One of the keynote speakers was Thobani, a veteran TAC activist who had worked with Miriam in the early years of the struggle for AIDS biomedicine; their images were on the banner - the backdrop to the day's events and a reminder of the legacy of MSF's trial in the face of South Africa's failure to provide AIDS treatment at the turn of the century.

When Thobani started ARVs through the MSF trial in June 2001 he weighed 30 kilograms and his CD4 count was 174. He reflected the skeleton of his story in a body map that he created, but did not complete, in 2003. In 2011, he participated in an initiative with the Departments of Public Works and Health, to create a new body map. The 2011 body maps track the journey of each artist's life since starting ARVs and have been placed in the waiting areas of Khayelitsha's new hospital as mosaics in 2012; like the activists described above, the artists' mosaics bear witness to the legacy of the struggle for AIDS biomedicine and the efficacy of PMTCT and ARVs in sustaining their lives over the course of the last decade. I discuss the body maps that were created across these two periods, first at the height of activism and then a decade after the introduction of ARVs in Khayelitsha through MSF's trial.

In this 2011 body map (below), and in his speech at the MSF 10 Year Celebration, Thobani notes the change in his health over the last decade: in 2011, his CD4 count is 622 and his viral load is undetectable. These biomedical indicators connect to the life cycles of HIV and ARVs as actants, with ARVs having successfully prevented HIV from co-opting CD4 cells and replicating, thus supporting the CD4 cells in sustaining his immune system. In the contours of his body, he has drawn his source of strength: a spear, represented by a red sheath and a white handle. This spear, he said when describing the symbols in his map, represented his isiXhosa heritage and the way that he was encouraged (particularly through traditional male circumcision) to be strong. This is reflected in the message that he wrote for other people living with HIV: Life is a challenge – face it. He attributes his emotional strength to his heritage and his physical strength to AIDS biomedicine. The white markings in his body symbolise his ARV tablets. He said, when discussing his body map, that he had been on ARVs for so long that they had

become part of who he is; that they were not simply pills that he put into his body, but that they were his body.

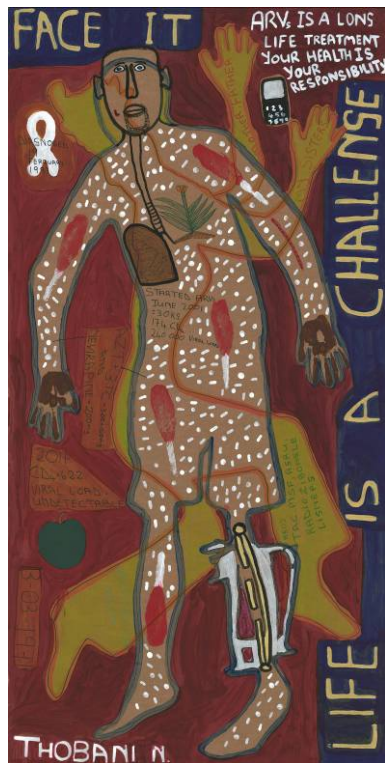


Figure 5.2. Thobani's Body Map
(Source: Thobani, 2011)

AIDS biomedicine had intra-acted so intimately with his body that he no longer distinguished between the boundaries of the medicine and the boundaries of his body – they had become each other. As an activist, Thobani had called on the state to intervene in the space of his body by providing medicines; with these medicines, he had not only resumed full health but had also come to embody ARVs so fully that he no longer separated the boundaries of the pill from the state of his body. His account draws into focus the biopolitical dynamic that linked the state of his body with the body of the state. Lambert and McDonald (2009) consider, similarly, the shifts in attitudes towards the body that have followed technological developments, particularly those that have the capacity to ‘remake life and death’ (Franklin and Lock, 2003). They challenge historical ‘representationalist’ approaches to embodiment in which

the body is separated from the social and understood to be a ‘slate for inscription’ (see Douglas, 1966). Similarly, this thesis moves away from a representationalist approach and towards a material-semiotic approach to embodiment because it disrupts binaries that distinguish between medicines and bodies, citizens and states. Instead, it foregrounds the entangled intra-action of HIV and ARVs with each other as they become the body.

Further, Thobani draws his cultural heritage, that of strength represented by a spear, within his body and alongside the ARVs that gave his body strength, disrupting dichotomies that separate the social from the science, discourse from materiality, human from non-human. Drawing on the definition of post-humanist performativity as “one that incorporates important material and discursive, social and scientific, human and nonhuman, and natural and cultural factors” (Barad, 2003: 808), Thobani’s account illustrates how a non-human actant, AIDS biomedicine, moved into and become a part of Thobani’s materiality, his body, and in turn played a role in the discursive performance of his wellbeing. Thobani’s discursive practices, his body map, his photograph on the MSF banner, his speeches in TAC marches and at MSF’s 10

Year Celebration, are aspects of Thobani's performance of activism and of health, precipitated by the presence of HIV in his life and his awareness of the value of AIDS biomedicine for sustaining his life. The visual depiction of his body filled with AIDS biomedicine, therefore illustrates the post-humanist dimension described by Barad (2003) as iterative intra-activity. Nowotny (2001), too, reflects on the extent to which scientific knowledge becomes integrated into everyday life because, as Latour (2005) writes, science is 'internal' to rather than separate from society. Here, Thobani's body map similarly illustrates the extent to which scientific knowledge moves beyond an abstract set of concepts into the very space of his body and outwards, too, through his activism and leadership within TAC, and speech at the MSF celebrations for example.



Figure 5.3. Bongiwe's Body Map
(Source: Bongiwe, 2011)

Bongiwe, too, spoke of the impact of AIDS biomedicine on her body and in her life through two body maps, one in 2003 and the second in 2011 (left). Bongiwe was born in 1975 in Guguletu, in Cape Town. She tested HIV-positive in August 2001 and started ARVs in 2002. When discussing her body map, she said, "It's nine years down the line and I'm still going strong. I'm not afraid to say that I'm HIV [positive]. This is my body map... Here I show what HIV looks like now. Before I said, in the previous body map, I said HIV looks like fire, you know it burns. I used to have a lot of pains at first, but now I feel like the fire has cooled down. That's why I show some coals here. It's coming down to ashes and it's thanks to ARVs." As a way to describe how ARVs 'cooled' the fire of HIV, Bongiwe echoed the other body map artists by referring to a set of biomedical indicators of relative illness and health that had changed between 2003 and 2011: "My CD4 count was 18 at the time, and I was weighing 48 kg.

This is me now, 2010, my CD4 count is 1045, my viral load is undetectable and I weigh 76 kilograms". Bongiwe's account suggests, as does Thobani's, that the self-care practices entailed in adhering to ARVs were embodied by resumed health, indicated through these biomedical markers.

These markers suggest an 'internalisation' of scientific knowledge generated through TAC's treatment literacy programme: as ARVs prevent HIV from changing its genetic material and

entering the CD4 cell, they enable healthy cells to support the body's immune response and quell the effect of HIV as a 'fire' that burns. MacGregor (2009a) reflects on TAC's treatment literacy initiatives in light of this group of women's body mapping and suggests that TAC's education activities reflect a 'context-sensitive' science. In the initial body maps, and now with this later set of maps, the narratives held in the women's body maps continue to reflect a sensitivity to the context in which people take ARVs; many of the women, for example, drew fruit and other foods on their maps and spoke about the importance of employment in supporting them to adhere to their treatment.

During this particular conversation, Bongiwe and I sat together with prints of the body maps on our laps and a pot of tea at our feet talking about the changes that had taken place in South Africa over the course of the past ten years. In Bongiwe's 2003 body map she had drawn a very much smaller body within the larger outline of her body map to describe how small and frail she was when she started ARVs. I asked her about the white marks she had drawn in her 2011 body map. She said, "These are the ARVs." Tracing her hand over the red contour of her body, moving in and out of the white circles representing the ARVs, she echoed Thobani, saying, "They're all over the body". Bongiwe's description suggests that the ARVs had, as with Thobani, become her body; by intra-acting with HIV, her ARVs were embodied in the fuller fleshier body she contrasts with her frail 'pre-ARV' self. However, at the time that Bongiwe started ARVs, she was conscious of accounts, fuelled by the former President and Health Minister, that ARVs were toxic and even deadly.

The following excerpt from our conversation illustrates Bongiwe's initial concern about taking ARVs and her unfolding relationship with ARVs. She was wary of the medicines as she did not know what they were going to do to her, but over time, they intra-acted with HIV to make 'pains go' and in doing this and showing her 'the way out' of illness, ARVs became her friend.

Me: How are you feeling in your body now?

Bongiwe: Yeah, great!

Me: And when you did your last body map?

Bongiwe: I did not have hope, but things now are different now. Because at first I was taking ARVs and I did not know what they were going to do to me, where they would take me to. Now I can see the way out. Now they are my friend.

Me: And the new message in your body map?

Bongiwe: It says shine where you are. You mustn't be afraid. Like they say: stomach in, chest out! ... The pains are gone, I'm healthy now. I'm fresh. It's like a Bongiwe that's risen up from the dead.

We looked up from the body maps and I said, "Like a Phoenix?" Bongiwe laughed and then we were quiet for a moment. "Like an Eagle," she said, waving her arms next to her as if she was flying.

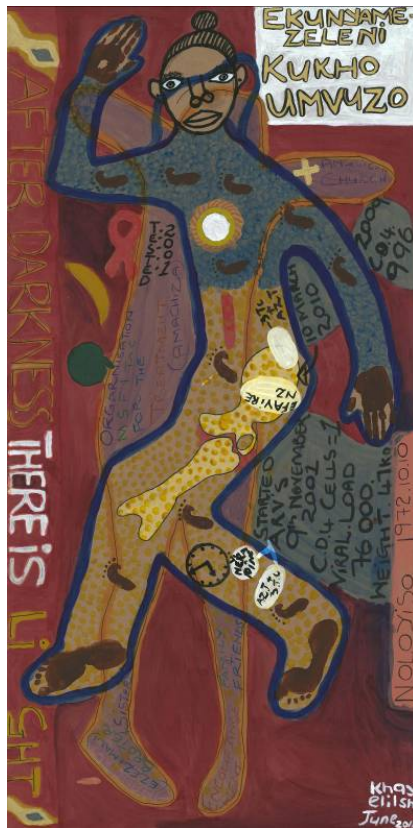


Figure 5.4. Noloyiso's Body Map
(Source: Noloyiso, 2011)

Across the body maps, ARVs were depicted as powerful non-human actants that had challenged the power of HIV within the arena of the body. Noloyiso, for example, spoke about her sense of ARVs 'calming' the storm of HIV within her body through her body map in 2011 (left). In her 2003 body map, she writes that was born in Tsolo, Eastern Cape, and tested HIV-positive in 2001. She started ARVs in the same year. Like Bongiwe, she describes how her health changed as a result of ARVs, between 2003 and 2011, with reference to biomarkers:

Before I started to take ARVs on 2001 my CD4 count was 1. My viral load was 76, 000. My weight was 47kgs [kilograms]. Before, in my other body map, I drew HIV: it looks like a storm. When a storm comes, it brings a lot of things: heavy rains; thunder storms; lightning; wind.

When your body aches, it's like falling of hairs, thrush, everything like that (Noloyiso, 2011).

A few weeks later we sat together with the two body maps and Noloyiso described the changes that had taken place in her body and in her life since we had last met two years before, and over the period spanning the creation of her two body maps. In her 2011 body map she has drawn small footprints that move up her legs, her stomach, chest and across her shoulders down her arms; the footprints in the upper part of her body are drawn against a backdrop of small blue waves. I asked her about her depiction of HIV as a storm in her 2003 body map and about the footprints and blue waves in her 2011 body map. In her response, she described how ARVs have enabled her to 'stand on' HIV, making it 'like nothing' to her now:

HIV is like nothing to me now. I'm not worried about it. Because I just see that it is calm. I show in this [2011] map that I'm walking up on - on top of - it. It's like the sand, you know, when you walk on the sand there is that mark... [With] wet sand it leaves a mark and then when the water comes it just wipes that mark. It's like the treatment that I already am taking has wiped the HIV. So now I don't feel like I have HIV. (Noloyiso, 2011).

Noloyiso's description of ARVs as radically transformative, an actant able to 'wipe HIV away', is a theme in many studies conducted just as ARVs became internationally available (Biehl, 2005, 2009, Rasmusen and Richey, 2012). Robins (2006), for example, refers to the 'treatment testimonies' of activists who give accounts of the 'lazarus effect' of HIV as they transitioned from bare life to full health. Their bare life was, as Robins argues, a result of the state refusing to provide ARVs and therefore withholding their citizens' ability to secure long-term vitality; he links the 'lazarus effect', however, to both medicines and the responsibilities entailed in taking them. Similarly, although activists like Thobani, Bongiwe and Noloyiso accorded agency to ARVs, as actants, in their embodied health I found, too, that their resumed health was linked to a set of complex disciplining techniques in which the activity of AIDS biomedicine with HIV within the body is played out, or performed. As Marsland writes,

From learning how to narrate their experiences to become 'therapeutic citizens' in Burkina Faso (Nguyen 2005), to the 'responsibilized' citizen-activists of the Treatment Action Campaign (TAC) in South Africa (Robins 2006), and the new social movements that worked with the Brazilian state to make ARV therapy available to all (Biehl 2004), these groups of people living with HIV have become known for their political radicalism, and docility in practicing new regimes of care that are oriented toward the requirements of the pharmaceutical (Biehl 2007) (2012: 471).

These 'new regimes of care' speak to Foucault's conception of 'technologies of the self' (1998). He describes the 'techniques of self' prescribed by ancient Greek pagan morality in order to condition sexual ethics. His work has been taken up by anthropologists researching biomedical regimes of care to show a contradiction in the practices required of those receiving ARVs (Kalofonos, 2008). For people on ARVs are told to follow a set of practices, a regime, that entail strict adherence to their medicines and healthy eating. Unlike the Ancient Greeks, Marsland (2012) describes the contradiction she observed in Tanzania as those people with whom she worked were not moving from a place of decadence and plenty into one of ascetic restrictions; instead, they were required by biomedical regimes of care to – almost impossibly – secure

scarce food and other material resources as techniques of ‘positive living’ on ARVs. As Kalofonos (2008) observed in Mozambique, ARV programmes can have ‘dehumanising effects’ for those who cannot afford to eat, but also cannot afford to take their ARVs without food because of the “torture of increased hunger pains brought on by ARVs in undernourished bodies” (2008: 364).

The people with whom I worked may have reflected Robins’ (2006) description of compliant and ‘responsibilised’ citizen activists who, when starting ARVs a decade ago, committed to following a set of practices entailed in joining the MSF pilot trial. However, a decade later, we see that these practices of self-care are fraught and not simply a matter of ‘compliance’ or ‘resistance’ to biomedical regimes of care among the people with whom I worked. Through her research in Uganda, also with people receiving ARVs, Whyte (2004) similarly calls us to pay attention to the different contexts in which social, economic and biomedical subjectivities unfold.

Returning to my own ethnography, context mattered. But I take context to matter both within and beyond the body, as I read the body itself as permeable. This deviates, slightly, from these emerging ethnographies (Kalofonos, 2008; Marsland, 2012; Marsland and Prince, 2012) that present a challenge to the politics of life literature. I do not only look at the socio-economic context in which people work to sustain their lives once on ARVs. I also look into the body to see how, as actants, HIV and ARVs intra-act in complex ways with each other to generate risk and also opportunity. For, as we see in the following two sections, a new set of struggles have surfaced that problematise both the context in which ARVs intra-act with HIV ‘within’ the body, and the context in which people live that, too, is precariously embodied. In Chapter Seven, I extend this discussion to explore some of the new forms of citizen practices that are emerging from these ‘new generation struggles’.

5.3. New Generation Struggles and Embodied Precarity

5.3.1. The Context of the Body: Side effects, Adherence and Viral Resistance

5.3.1.1. “My treatment is killing me”: Side Effects

Accounts from the journey maps, body maps, interviews and ethnography point to the precarity not only generated by HIV but also by ARVs. Miriam, for example, frequently spoke about how “my treatment is killing me”. One day she brought me the information sheet that

was included in the tub of her alluvia (lopinivar/ritonavir combination) tablets and showed me the section under side effects where it said that alluvia is associated with gastrointestinal side effects. Stabbing her finger at the sheet, she asked, “And they expect me to take this and just shut up?” Miriam struggled with her weight and attributed this struggle to the effects of her treatment. Her frustration was exacerbated by her sense that the health care workers dismissed her health concerns as a consequence of her weight. In addition to feeling that her general health concerns were not taken seriously, she also felt that her concerns around the side effects of her treatment were not taken seriously.

Lilian experienced difficulty with a number of her ARVs and also struggled to be taken seriously when raising her concerns with doctors. She said, “If you’re a patient, they will take you as if you’re mentally ill.” Miriam and Zama, unlike Lilian, had first started taking ARVs through the MSF trial; they both recounted a shift as they moved from a relationship characterised by respect with their MSF doctor to one that was, largely, characterised by suspicion and mistrust with their clinic doctor. Although Lilian wanted to ‘work with’ her ARVs, and had been careful to adhere to practices of ‘positive living’, she was frustrated that when her ARVs no longer worked for her she was not taken seriously by her doctor. She went on to explain how she experienced health care practitioners as punitive and explained how this form of communication has ramifications on the knowledge that health practitioners withhold from patients:

We make mistakes but we deserve to be treated in the right way. Like if I miss my dates, I will be shouted at by the nurses that if I miss my dates, I will die. And no one wants to be reminded that she will die. Sometimes if the doctor finds something wrong they won’t tell you, they just write it down in the folder to the pharmacist without telling you ... that you must change your medication. They will just send you to the pharmacy, without telling you why you must change the medication (Lilian, 2011).

Her words suggest a shift away from a collaborative form of health care that the women experienced when on the MSF trial to a distrustful, defiant approach to health practitioners in the public sector. In their research in rural areas of South Africa, Schatz and Gilbert (2012), found that an abiding sense of distrust between women and health care practitioners deterred many from seeking medical care; and in Tanzania, distrust between HIV-positive people and health care workers was found to actively undermine access to ARVs (Agnarson et al., 2010). In my research with activists and with those who had not been activists (but who were on ARVs),

I found that people had complex and frequently problematic encounters with their health care workers.

Yvonne traced her treatment biography on a piece of large piece of paper with me, telling me about the different effects of the 'nukes' and 'non-nukes'. Nukes refer to nucleoside/nucleotide reverse-transcriptase inhibitors (NRTIs/NtRTIs) and non-nukes refer to non-nucleoside reverse-transcriptase inhibitors (NNRTIs). This colloquial terminology points to a discursive construction of AIDS biomedicine as a weapon in the war against HIV and reflects a broader discourse employed by AIDS activists around 'the struggle for ARVs'. It also connects to Sontag's cautionary discussion of metaphors that perpetuate myths and reinforce stigmas by 'blaming the victim' (1988). 'Nukes' and 'non-nukes' are not, as argued throughout this thesis, autonomous technologies and they have different effects on different bodies. This description belies variable effects of biomedical technologies and may enable a 'blaming', described above by Lilian, by placing responsibility on the individual for developing viral resistance or experiencing side-effects and not on the interaction of pathologies with medical technologies, bodies and their social context. The muddy, non-linear pathways in which people do not simply resume health on ARVs, but also experience a range of struggles with these medicines, confound the earlier activist discourses, mobilised globally, in which ARVs were cast by biosocial groupings as a 'technofix'.

There was a disjuncture in how the groups of people I worked with navigated these new generation struggles as citizens, and I discuss this in detail in Chapter Seven with respect to biosocial fragmentation and emergent citizenships. The women in the core group, who had been AIDS activists, found strategic ways to manage difficult and distrustful relationships with their doctors who were, ultimately, the gatekeepers to their ARVs. The people I worked with who had not been AIDS activists, however, said that they preferred to 'just keep quiet with my doctor'. Lilian and Yvonne both experienced lipodystrophy on their initial treatment regimens and were able to negotiate with their doctors to change their medicine. Their proactive engagement with medical practitioners was anomalous to the overall finding that people struggled to discuss and negotiate their concerns around ARV side-effects with medical practitioners. It was perhaps, as Lilian herself remarked, their history of activism with TAC that had "made us strong enough" to negotiate their "right to the right medicines" (see Mbali, 2013). Yvonne said, proudly, that the doctors and nurses in her clinic knew that TAC "would cause trouble" if they did not respect the rights of their patients and take their concerns about side effects seriously.

Yvonne has changed her treatment regimen twice as a result of side effects. First, she moved from zidovudine (AZT) and nevirapine (NVP) on to stavudine (d4T) and efavirenz (EFV) because she experienced liver damage and anaemia. Lipodystrophy, or the redistribution of body fat, was a commonly experienced side effect on d4T among the research participants. Yvonne, too, experienced lipodystrophy but because her biomedical 'health indicators', like her viral load, had remained the same, her request to change her medication was met with a threat to move her on to second line treatment. She describes this process in relation to the new generation of struggles that are emerging with the ARV roll-out:

Sometimes people get bored because it's a life-long treatment... Also side effects: I've experienced side effects on d4T. I tell myself that if the doctor doesn't want to change me, I'll stop taking ARVs. It's a reminder now, I've accepted my status and that's ok. But if every time I look at myself and I see I'm not the same person I was before, it's a reminder. So I tell my mother if they won't let me take a new treatment, I will stop. And if I can write it in my folder, I will say I stopped because they didn't change me... Although my shape had changed, the viral load is suppressed, so he told me that I need to continue with ARVs or he will put me on second line. I think that they feel if you are impatient it's because you don't have information. It's only them who have information. I knew that I must change to TDF [tenofovir]. So I challenged him. That's when he said I must go home and that he would discuss with other doctors. Then early in the morning, I was there, waiting in front of his door, and I was to find out he never consulted other doctors. He only consulted them when he saw me waiting in front of his door, and they said if I have a problem I must be changed, and he said, ok I will change you (Yvonne, 2011).

Here Yvonne described how the side effects make her aware of her HIV-status by showing her that she was not the "same person I was before". Lilian also experienced lipodystrophy, or 'lipo' as she referred to it, but she experienced it as a result of AZT and not d4T. In addition to feeling 'outside' her body, a body that did not feel like it was her own, she also raised the issue of signification.

Like Yvonne, Lilian described her sense of alienation in her body and spoke of her compassion for people who experience a range of other side effects that 'mark' their HIV, inadvertently disclosing their status to people around them through markings on their skin, for example.

Yes we need the medication. Yes medication is going to have side effects. But still, are we going to ignore the fact that these things [side effects] when they are showing we

are fine with them? I'm not fine with the fact that I've lost my booty, I'm not fine with the fact that I'm losing flesh on my legs. No! In my case I'm empowered: I'm an activist. When I noticed something was changing in my body I went to my doctor I spoke to my doctor... I told him, 'You're taking me out of this!' Not everyone is empowered to notice and to go to the doctor... [I]t works on you psychologically... The same with the nevirapine side-effects: you develop the Steven Johnson syndrome. What does it say? It says everybody can see there's something wrong with you (Lillian, 2011).

Like the previous struggle for AIDS medicines, these 'new generation struggles' are also embodied as a form of biopolitical precarity, and continue to require strategic negotiation between health care workers and citizens as they navigate their right to health care within the public health system. These struggles are, however, even more complex because they call attention to the myriad effects of ARVs beyond the earlier assertions of their 'lazarus effect' in bringing people 'back to life'. The struggle for ARVs was a clear one: without ARVs, people would die. Now, struggles around side-effects, and as I go on to discuss, around viral resistance and treatment fatigue, are more difficult to mobilise around because they are embodied differently.

5.3.1.2. "You feel tired!": Treatment Fatigue and Viral Resistance

During my fieldwork with TAC, it became apparent that branch members across the country were raising concerns around adherence, side effects and viral resistance. In an effort to address these concerns, and to call on the government to introduce new biomedical technologies (for TB and HIV), we developed an Equal Treatment issue on these 'new generation struggles'. Nathan Geffen wrote the editorial for this issue. Writing about the life cycle of HIV, he described how both ARVs and viruses are constantly changing inside the body. These changes, wrought through the intra-action of older ARVs with an agile shape-shifting virus, underlined the political imperative to bring new generations of ARVs to South Africa in order to reduce the risk of side effects, to increase the likelihood of adherence and to provide third line treatment to people who have developed resistance to second line treatment. His article reflects a conception of HIV as an actant, as "particular kinds of germs" that change, evolve, mutate. He describes this process of intra-action in the excerpt below:

Medicines are developed to attack particular kinds of germs. But over time germs change; they evolve; they mutate. Sometimes they change sufficiently so that the

medicines that are supposed to be effective against them stop working. This is natural; it's the way the germs work (Geffen, 2011: 1).

The fear of developing resistance to second line treatment permeated my fieldwork with people who were on second line treatment, or who had children on second line treatment. A number of the activists I engaged with through the course of my fieldwork referred to a prominent activist who had also become tired and who had 'given up' taking his medication; it was a shock to them because he was well informed, worked to raise awareness around the efficacy of AIDS medicine, and yet had reached a point where he was too 'tired' to continue taking his treatment. His treatment fatigue was also compounded by depression and alcoholism: he became very seriously ill with meningitis and asked to be placed back on ARVs, but by this stage his body had developed resistance to both lines of treatment and he died. Geffen reflects the importance of activism to compel the government to these less harmful and more effective biomedical technologies, including third line treatment like raltegravir, in the following statement: "TAC's work in the next few years is therefore clear: we have to help get access to drugs like raltegravir... Making these drugs accessible will save many lives" (Geffen, 2011: 1). I discuss the policy implications of making these drugs accessible in more detail in the final two ethnographic chapters around citizenship and the international governance of medicines.

Treatment fatigue and viral resistance are two inter-linked 'new generation struggles' that emerged in my fieldwork. Participants frequently used the term 'tired' to describe their frustration with taking medicine every day at a particular time. Brenda, for example, decided to 'take a break' because she was tired of taking ARVs. During a conversation about the current government and changes in the politics of health, she said,

If Zuma could try to get third line I think it's good for us, or an injection. Because tablets are not easy to take. It's not easy to take ARV tablets every morning. That's why they have a lot of defaulters. So I think Zuma must try again or try harder to get something to help us. Because ARVs, wow! They're good, but if you take tablets... Yoh! You feel tired! But if I'm getting injection for a month to protect my virus, I think it's good for me (Brenda, 2011).

As a result of interrupting her treatment, the virus had mutated sufficiently to outwit her first line ARVs and she was therefore placed on second line treatment.

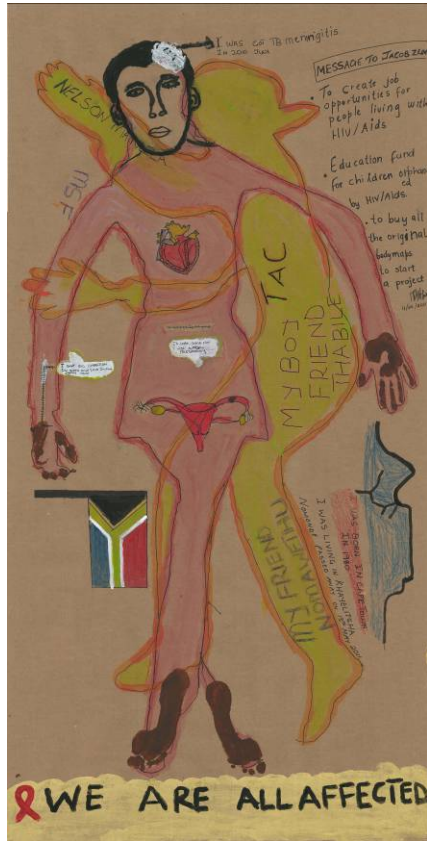


Figure 5.5. Nomonde's Body Map
(Source: Nomonde, 2011)

Nomonde was one of the seven people commissioned to develop new body maps in 2011. Her story did not map a linear trajectory from illness to health as a result of ARVs; instead, it highlights the precarity of living with HIV and the points to the limitations of AIDS biomedicine for extending life. Her map, unlike the others, is not complete because she died in the course of creating it on 13 May 2011. Her life started in Cape Town in 1980, as represented by the outline of Table Mountain on the right hand side of her body map. Her message to other people, placed below her feet against a gold background, is: "We are all affected"; echoing this assertion of inter-connection, her death rippled across the group of people she had known as an activist and as a friend. The importance of sociality, of shared care, is

iterated in the process of developing the body map: each body map is created in dialogue with another

person, as shown through the two outlines of bodies on each of the maps. Underlining the importance of sociality, each person wrote down their sources of support and inspiration in the outline of the person who assisted them in creating their body map. Nomonde writes that her sources of support were her boyfriend and TAC, and her source of inspiration was Nelson Mandela. On her own body, there is an arrow from her head to text that says: "I was got TB meningitis in 2010 July".

The accounts of her death varied according to each person I spoke to. On the evening of her death I was told that she had been so tired after seeing her doctor at the clinic that she had laid down on a bench, fallen asleep and died. Another friend said that she had died of depression and isolation: Nomonde had been in hospital for a year in 2010 because of TB meningitis and when she was creating her body map, she had spoken of her loneliness in hospital, her despondence with HIV and her frustration with ARVs because they had not protected her from the effects of HIV. A third narrative account of her death related to Nomonde's increased interest in traditional medicine and her sense of the limitations of biomedicine, and antiretrovirals in particular. She had started training to become a traditional

healer, believing that her chronic illness was an indication from her ancestors that she should follow this route; that she should become a healer in order to become healed. Nomonde's 'tiredness', depression and frustration with both chronic illness and with AIDS biomedicine, permeate these accounts.

Beneath the explicit narratives were implicit wonderings, unspoken thoughts linked to 'giving up'. Nomonde's death prompted reflections from her friends, also research participants, about their own corporeal vulnerability; that AIDS biomedicine could ward off the effect of HIV for a time, but that ultimately the length of this time was finite. The move to consider HIV as a chronic illness paralleled the provision of ARVs in the global north far earlier than most countries in the rest of the world (with the exception of Brazil). When South Africans like Nomonde were using body maps as an activist strategy to bear witness to the effects of HIV as an acute disease, research in northern America heralded some of the psychosocial implications of living a long life with HIV. Siegel and Lekas (2002), for example, researched the implications of living with HIV as a chronic illness, and similarly note how HIV-positive people remained vigilant to any possibility of resumed illness, constantly aware of the potential for HIV to engender their embodied vulnerability. More recently Greenhalgh (2009) suggests that managing HIV as a chronic illness requires us to move away from locating medicine as the 'fix' to the problem of HIV, to a more contextually informed understanding of patient care and self management. Historically, self-management programmes have focussed on the individual, placing responsibility on patients to manage their health; in contrast, Greenhalgh (2009) draws on a social ecology approach in which illness is understood to emerge from an interplay of factors in a complex system. This reflects the previous chapter's approach to exploring the linkages between epidemiological framing of HIV transmission and the social pathways that HIV travels to enter people's bodies. Nomonde's death highlights the importance of social support, through friends, but also through organisations like TAC, in recognising the multiple struggles that flow from accessing ARVs and managing life with a chronic illness.

5.3.2. The Body in Context: (Un)employment and Economic (In)security

The artists of each of the body maps represented HIV in different ways inside their bodies. Bongwiwe, for example, drew HIV as the embers of a former conflagration, saying that ARVs had 'cooled' the fire down. Nloyiso described HIV as the soft indentations of footprints on the wet sand, saying that ARVs had 'calmed' the storm of HIV down. In contrast with all of the body maps developed in both 2003 and 2011, Nondumiso drew HIV outside her body. She said that

now HIV was not what defined her and that, instead, it was a source of opportunity for her. HIV was symbolised by white ribbons around her body. Inside the ribbons she had drawn maple leaves; the leaves referred to the artistic collaborations that she had entered into with colleagues in Canada through her HIV activism and art. Her body map extends Thobani's description of ARVs as his body. Nondumiso, in an interview about her body map, said that ARVs had been so powerful that they had moved HIV outside her body. She pointed to the marks on her body, shown in the map as light brown markings along her legs and arms, saying, "Yes, the effect of HIV is still on my skin, but HIV is not who I am."

This marks a key shift in socialities as Nondumiso both claimed HIV through the kinds of opportunities she was able to access, while also asserting that she did not want to be fundamentally labelled as 'HIV-positive'. She said, instead, when telling the rest of the group of artists about her map, that she wanted to be thought as, "Just someone living with X. X is my child, or my art. I'm not my HIV." This further reflects Whyte's (2009) call to understand how subjectivities shift as people's embodied experience of illness changes. In Nondumiso's case, her experience of illness changed markedly after she accessed ARVs in 2002. Ten years later, I visited Nondumiso, Bongiwe and Thobani at an exhibition in London. They had worked with



Figure 5.6. Nondumiso's Body Map (Source: Nondumiso, 2011)

the British Council, in conjunction with the Paralympics, to develop a body of work with a British artist, Rachel Gadsen. I watched a performance, as part of this exhibition, where HIV took the form a dancer's body as she flew around the stage, wild and dangerous, before ARVs – another dancer – came to tame her. In the discussion following the dance, Nondumiso, Bongiwe and Thobani engaged with an audience of about 500 people. Nondumiso spoke about her vision as an artist and her dream to create better education for youth in South Africa; she did not discuss HIV, nor was she asked to. In contrast with the body map exhibitions in South Africa, New York and London during the struggle for ARVs, this exhibition was not linked to her and her colleagues' experience of HIV. Rather it was a testament to their artistic creativity and capacity to create beauty from their

experience of life beyond (but inevitably including) their chronic illness.

As we see above in Bongiwe and Thobani's accounts, it is through the intra-action of ARVs with HIV that Nondumiso was able to see HIV as 'beyond' her body. It is also, as I discuss above, through her discipline and self-care practices, particularly around adherence, that she was able to manage HIV to the extent that she could 'see' it outside herself in the opportunities she was able to access. This presents another layer to the discussion above around Thobani's body map and post-humanist performativity as ARVs intra-act with HIV: it is through taking ARVs, every day, that Nondumiso 'saw' the presence of HIV in the form of her ARVs even as it was felt to be absent from her body. A tension therefore surfaced for Nondumiso between wanting to move away from being defined by HIV, and the struggle for ARVs, and recognising that ARVs also enabled her to move 'beyond HIV'. She spoke of this tension at length in the course of our work together, and spoke too, of her frustration with her sense that people also patronised her and overlooked her skills because she was HIV-positive and a woman.

This tension was a strong finding in my ethnographic research with the women in the core group and I discuss the economic dimensions of this tension below. In contrast with the notion of 'bare life' described by Robins (2005) and generated through the state's historical failure to provide essential AIDS biomedicine, the way in which precarity was strategically performed by the research participants points to a different narrative. In connection with the previous chapter's discussion on pathways of precarity, I suggest that instead of being either reduced to bare life or 'acted on' by national and international development programmes, women 'acted up' by strategically placing themselves within the 'development subjectivities' that had been discursively narrated through development interventions and policies that framed women as economically, socially and biologically 'vulnerable' to and as a result of HIV-infection.

In the early months of 2011, my conversations with TAC's staff in Khayelitsha and Cape Town rippled with the news that the Global Fund had stalled on the final payment (R15 million) to the National Department of Health (NDoH) (R7 million was finally paid in March 2012). This, along with shifting donor priorities, had very real and negative ramifications for those working in TAC and other recipient organisations: Lilian, Yvonne, Zama and Judith all worked in recipient HIV organisations and they were all retrenched by the end of 2011. These women had all been instrumental in the activist work around access to ARVs in South Africa, just as activist organisations like TAC had been instrumental in their lives and career trajectories. As

described above and in the previous chapter, Lilian spearheaded TAC's campaign to compel the government to provide PMTCT treatment. Both Lilian and Thandiswa testified on behalf of TAC and their affidavits were used as evidence in the court case. Lilian, like Zama, worked with an HIV treatment literacy organisation and had been extensively filmed on the Siyanqoba/Beat It! television series (Hodes, 2007).²¹ In March 2012 I sat with Lilian in Cape Town's summer sunshine, catching up on the past few months since I had completed my fieldwork and left South Africa. In the intervening months since I completed my fieldwork Lilian had lost her job along with the other three women working in the AIDS activist field. I understood that Lilian had challenged the poor working conditions of her employment, the long working hours at a low wage. She was told that she was being unreasonable given the demand for employment in South Africa's context of high unemployment and poverty; an impasse ensued and her contract was terminated. As a result of losing her job, Lilian had to cancel her lease agreement on her home and move back to live with her sister in Khayelitsha. Not wanting to lose her son's place in his school and risk having to send him to a school in Khayelitsha with fewer resources, Lilian wakes up at 4am to get her son dressed and ready by 5am in time to make the long trip with public transport to his school. "I don't breathe until he gets home in the afternoon. You know what the townships are like for children".

Women like Lilian, Judith, Thandiswa and Zama who were employed through the HIV activist machinery were the first people to feel the consequences of the turning tide in funding restrictions and donor priorities. Despite extensive work experience in the field of HIV activism, prevention and treatment literacy, formal education surfaced as a key factor informing their employability. This circles back to the complex feelings that Nondumiso expressed above: she saw HIV 'outside' her body in the professional opportunities that she accessed, like travelling to Canada and to the UK as an artist and consultant in body mapping methods. While not wanting to be defined as 'living with HIV', it was through being HIV-positive that she was able to express her passion for art, and her desire to connect with other artists globally. Lilian and Judith also resisted the way they were typecast: not only did they resist the 'HIV-positive' label, but they resented their employers' racist and sexist assumptions that they believed were attached to the composite term 'Black, uneducated women'. With one employer, whom they shared in the work they did on a HIV research project, they resented his assumption that they were not in a position to negotiate the terms of their employment. They were even angrier that this assumption was partly accurate because they were not in a

²¹ The series is structured around a support group of HIV-positive people and each week they discuss a different issue related to HIV, including gender-based violence, stigma, and women's reproductive health rights, for example.

financial position to challenge the unfair terms of their employment or the unfair assumptions that, they said, underwrote these terms.

The sources of precarity described in the previous chapter resurfaced in Lilian, Judith, Thandiswa and Zama's retrenchment. Technical phrases like 'formal education' conceal complex histories of these women's struggles in rural schools providing 'bantú education' in the Eastern Cape and as young girls who were sexually violated and abandoned by their family. These phrases work to render women as faceless, unreal, against whom structural violence can be legitimated, in this case, through retrenchment. This connects to Farmer's description of suffering that "is 'structured' by historically given (and often economically driven) processes and forces that conspire – whether through routine, ritual, or, as is more commonly the case, the hard surfaces of life – to constrain agency" (2005: 40).

Structural violence was also legitimated by explicitly and strategically drawing on women's vulnerability to propel company profits by exploiting HIV-positive women's labour. This emerged in the course of my fieldwork with the other six women who worked with *uYaphi*, a so-called 'HIV empowerment organisation'. *uYaphi* set out in the late 1990s to provide employment opportunities to HIV-positive black women on the understanding that this group was most vulnerable to the impact of HIV in South Africa. Miriam, Thandiswa, Yandisa, Zolani, Sibongile and Brenda all derived their main income through the paper mâché bowls they made for *uYaphi* each week. Each woman had been funnelled into *uYaphi* through support groups that they had joined when they started ARVs. At first, in the late 1990s and early 2000s, the women acknowledged that the organisation had worked respectfully with them, paying them a decent wage for their work.

With the shift in management in 2006, the Income Generation (IG) programme became focussed on selling products internationally to increase their profit margin. The IG manager explained that although the women were not given an increase in payment per product, they would benefit from increased sales by receiving larger orders. The women I worked with told me that they had not received an increase in pay for five years. According to Miriam, every time they raised this issue, the IG manager "uses words and drawings and treats us like children but doesn't actually explain anything or listen to what we say". Miriam became increasingly angry with *uYaphi* in the course of my fieldwork, and eventually challenged the manager directly and told him that he was, "exploiting my HIV". Miriam claimed that she was punished the following week when she received an inordinately low order for bowls. Yandisa,

one of the oldest women working at *uYaphi* and a close friend (and neighbour) of Miriam's, also challenged the manager during a period of heightened contestation around wages. She asked him why a white man was running an income generation programme for Black HIV-positive women; his response was that there were no suitably qualified Black women to take his position. When I saw the women after this exchange they were both outraged by and resigned to his power; they recognised that there was no space for engagement or negotiation, and were concerned about the financial implications for continuing the struggle with *uYaphi*'s management. They did, however, irk him as often as possible by speaking about their frustrations with him in isiXhosa when he was in the same room; this frustrated him and gave an indirect power to the women, because although he heard his name he did not speak this language and was powerless to directly challenge them as he had no basis on which to claim they were being disparaging.

The IG manager boasted a R24 million turnover in 2010 and said to me, repeatedly, "The women must just get with capitalism". As he was explaining the women's short-sighted business acumen, he answered his smartphone and discussed the fencing that he was erecting around his pool at home. He then went on to explain the model of the IG program: the women who made the paper mâché products were classified as 'self-employed' and not as employees of the organisation. This way, he explained, the women were not entitled to any legal employment benefits and any negotiations that did take place were at the discrepancy of *uYaphi* and a good-natured sign of their "willingness to help where they could". The little brochures that are glued on to all the products speak about the women's lives, their poverty, their experience of gender inequality, and places the imperative on the buyer to "do the right thing by the women by buying the bowl".

Seeing the absence of state-machinery in their lives beyond their ability to access ARVs and grants, the women shifted their precarity through performance into a resource that facilitated access to the HIV activist and employment sector. I consider the way women engage with these structures as an example of performativity because they tactically navigated a set of restrictive, even oppressive, structures by subverting them. This performance was based on a strategic recognition of the development sector's construction of the HIV-positive other: the at-risk-population group of poor, Black women in South Africa. A set of struggles, resonant with Hacking's (1990) notion of a 'looping effect', proceeds from this apparently strategic mobilisation of precarity as women resisted the labels of poor, Black and HIV-positive, and

came to resent the way that organisations benefited from their participation by using these labels, by exploiting their HIV.

In thinking about the absence or presence of the state (I discuss this in detail in Chapter Seven), these women's strategies connect with de Certeau's (1984) conception of 'making do' as people employ a set of tactics to navigate precarity wrought through repressive or absent state structures. He looks, for example, at the hidden struggle of indigenous people in South America as they resisted Spanish colonisers, suggesting that,

Submissive, and even consenting to their subjection, the Indians nevertheless often made of the rituals, representations, and laws imposed on them something quite different from what their conquerors had in mind; they subverted them not by rejecting or altering them, but by using them with respect to ends and references foreign to the system they had no choice but to accept (1984: xiii).

This account also connects to the women's use of language as a means to exclude the IG manager from their discussions, and to – albeit indirectly – challenge his authority. The struggles around performing and resisting precarity linked to HIV indicate that, on the one hand, it is possible to utilise the power of categorisation in order to secure resources, in this case economic capital. All of the women I worked with in the core ethnographic group were able to secure a degree of financial autonomy through their work in HIV activist or non-governmental organisations. On the other hand, these findings also reflect the danger of operationalising responses to the 'gender and HIV' dyad, particularly within NGOs that may 'exploit our HIV', without critical reflection about institutional capacity to reinforce rather than challenge structural inequality.

5.4. Conclusion

The ten year celebration of MSF's first ARV trial in Khayelitsha was a poignant and powerful marker of transitions in South Africa's biopolitical landscape: at the time of my fieldwork, ARVs were no longer the scarce resource they were when people like Miriam, Thobani, Bongiwe and Nondumiso first started taking these medicines a decade ago. It is for this reason, I propose, that we start to see a shift in the embodied accounts of the intra-action of HIV and ARVs in people's lives. I refer to embodied 'accounts' here as it was through hanging out, and in verbal and visual narratives (in the body maps) that the people I worked with communicated how they embodied these actants in their lives, over this last decade. This chapter traced these fluid accounts across time, and in relation to two groups of people with whom I worked most

closely during my fieldwork: the Bambanani Women's Group and the core group of women. It is therefore with the understanding that I worked with this particular group of people, who had engaged as activists in the historic context of the struggle for AIDS biomedicine in South Africa (as described in Chapter One), that I situate the following observations.

I suggest that if we really are going to move beyond the 'nature/culture' dichotomy that separates biology (the embodied dimension of this thesis) from socialities (the political dimension), we need to explore how the world 'outside' the body permeates and shapes life 'inside' the body. This requires a shift away from privileging 'biology' as that which exists inside the body to recognising, through the lens of biopolitical precarity, how the body is porously networked into an assemblage that brings the 'outside' 'inside'. To this end, this chapter juxtaposed interiority with ethnology: it looked between the world 'inside' and the world 'outside' the body. The first section explored how HIV and ARVs, as actants, move into relationships with each other within the body; and it illustrated how these actants are also brought into the body through socialities that take place between multiple actors outside the body, in relationships between the people I worked with, TAC, MSF and the government. The socialities that were formed among the people with whom I worked around their HIV status was a strong feature of my fieldwork as I observed and took part in the networks of connection that brought friends and colleagues together.

The timing of this ethnography, a decade after MSF first introduced ARVs through the trial in Khayelitsha, calls into focus the trajectory of ethnographic research on biosociality and biopolitics – in my fieldsite and elsewhere in Africa, particularly linked to the provision of AIDS biomedicine through large-scale public programmes. For example, anthropologists like Steven Robins (2005, 2006) and Vinh-Kim Nguyen (2005, 2010) considered how HIV-positive people, in Khayelitsha and Ouagadougou respectively, cohered around the biopolitical struggle for these essential medicines. In my research, I found that a new set of biopolitical struggles flowed from the success of the struggle for ARVs. As discussed in the accounts of embodied precarity above, the well-trodden paths linking friends together through their historic struggle for ARVs persisted; but the nature of their relationship and the kinds of things that mattered to them, had diffracted away from a narrow focus on the politics of life linked to AIDS biomedicines. For, these conversations were about the previous year's football world cup, and each other's love affairs; frustrations with doctors, and daily struggles to find taxi money to pay for children to get to their school. Although these relationships may have originally been formed through the shared experience of embodied precarity linked to the absence of ARVs, followed by the

joint actions within TAC, these forms of biosociality seemed to have moved on with the conversations as they, too, shifted away from this political history and into a new biopolitical era characterised by 'new generation struggles'.

We see in this and the previous chapter that HIV and ARVs offer both risk and opportunity as they intra-act with each other and are differently embodied over time. It was therefore not productive to only consider biosociality in its historic reading in South Africa, in relation to the biology of HIV and the groups of people who formed relationships with each other in order to call on the state to access ARVs. This chapter suggests that it may be productive to look at diffracted biosocialities: these are socialities that move out from relationships formed around HIV, to include set of relationships that include those of actants (and their social lives) within the body, and actors (and their social lives) outside the body. These diffracted socialities relate to the dual character of the new generation struggles.

The first set of 'new generation struggles' were linked to precarity engendered through AIDS biomedicines and difficulties with side-effects, adherence and viral resistance; this aspect of the new generation of struggles points to the limits to the construction AIDS biomedicine as a 'technofix', or as autonomous entities that have uniform effects on bodies that are everywhere the same. Other studies on ARV programmes elsewhere in Africa have also observed emergent struggles around AIDS biomedicines, including trends of 'noncompliance', or failure to adhere. For example, Ezekiel, Talla and Klepp (2009) explored how people constituted ARVs through local discourses about illness and healing in order to understand attrition on ARV programs in rural Tanzania. Their study found that the transition from severe illness into health could prompt stigma, as people came to embody ARVs and started to "look fat and HIV-negative" thus inadvertently disclosing that they were previously ill because they were HIV-positive. The researchers also found that people "failed to adhere" because they simply did not understand the positive therapeutic effects of ARVs on their body. The effects of ARVs that they did experience, however, were cast in light of their faulty 'local knowledge', thus effectively dismissing their very real experiences of these medicines by distinguishing between 'incorrect' local understandings and 'correct' biomedical knowledge. The researchers did not explore why people may have been ambivalent about the myriad effects of ARVs on their body, but instead drew on a deficit model of science and assumed that they simply required education in the biomedical efficacy of biomedicine, thus effectively blaming the individual rather than engaging with the complex dynamics that ARVs engender in people's bodies and lives.

In another study on ARV adherence, researchers similarly claimed that ‘false beliefs’ were to blame for treatment failure among almost 400 people on an ARV program in Livingstone, Zambia (Nozaki, Kuriyama, Manyepa, Zyambo, Kakimoto and Brnighausen, 2013). The discourse of ‘false beliefs’, ‘failure’ and ‘noncompliance’ in these studies indicates another level at which governmentality operates, not only through the public health system but also through those studying it: through this discourse of ‘blame’, we see how the discipline required of patients when entering ARV programs places responsibility on the individual to follow a set of established protocols and when they ‘fail’ to follow these protocols, they are labelled as noncompliant.

Anthropologists like Marsland (2012), Prince (2012), Meinart (2003) and Le Marcis (2012), who have also researched ARV programmes in Eastern and Southern Africa in the decade following the initial struggle for ARVs, have suggested a reframing of the historical approach to governmentality, biosociality and biopolitics (see Robins, 2006; Nguyen, 2010). In a special issue on medical anthropology and biomedicine, these anthropologists reflect on their research and probe the limits of biopolitics as a ‘one size fits all’ conceptual approach. In response to the assertion that “biosociality does not look inward to the body, but outward to human relationships” (Marsland, 2012: 473), this thesis suggests that perhaps there is a way of thinking about biosociality that does not ask us to look either into the body, or outward to socialities, but across them.

In conceptualising HIV and ARVs as actants, this thesis draws the social dimension of their lives into relief; further, the dual character of the new generation struggles bring the biological dimension of social, political and economic relationships into focus. For HIV not only enters women’s lives, as we saw in the previous chapter, through human relationships, but as an actant, HIV itself becomes alive and has, in Appadurai’s (1988) terms, a ‘social life’ in the body. Once in the body, the virus learns to intra-act with the body’s immune system – its CD4 cells – and, over time, manages to con these cells into mimicking the body’s basic biological identity – its DNA. ARVs, like HIV, also call attention to the social, economic and political relationships that women navigated as activists in order to mobilise the government to bring these medicines into South Africa’s public health system. However, once in the body, ARVs also take on a social life. They each interact with each other as they are technologically honed – as a triple therapy – to block HIV in its attempts to con the CD4 cells.

Where my research perhaps connects to, but also moves from, this new work on biosociality is that, as actants, the social lives of ARVs are not solely embodied in positive terms (described by Nguyen (2005, 2010) and Robins (2006), nor do they highlight the limitations of biomedical programmes in places where people can sometimes simply not afford to take medicines that make them even more hungry and even less able to work (described by Marsland and Prince (2012), for example). Thinking about ARVs as actants, things with a social life, highlights another form of sociality as they become felt by the people I worked with, and visible to other people, through their manifestation in side effects, like lipodystrophy. What is held in the body becomes social.

These actants intra-act and move into the social space of people's relationships with each other as they become visible as facets of sociality: through activist networks that mobilise around AIDS biomedicines; around ARVs as they become embodied in people's physiological health and parallel side-effects; through the kind of sexual relationships that women can and cannot negotiate with their partners; through the economic resources they are able to secure by foregrounding one particular subjectivity – HIV – over the multitude of others; and through the emerging citizen claims that draw these women back into a biopolitical relationship with the state to access newer medical technologies that will have fewer negative effects on their bodies and that will be better able to combat HIV as it learns to outwit the older generation medicines. Therefore, I use the term 'diffracted biosocialities' to describe a dynamic connection across these facets and to denote the complex ways in which the social is not only forged through biology, but where biology, itself, is social and forged through sociality.

The second character of the new generation struggles discussed in this chapter relate to the socio-economic contours of these women's everyday lives. We see, in this strand of the new generation struggles, how HIV can and has been used performatively to secure, albeit precariously, resources through which women have been able to navigate the tightly stretched economic landscape in which they live. The previous chapter describes and critiques the construction of women as vulnerable 'victims', biologically and socio-economically more susceptible to HIV infection than men. This chapter considers, too, how women work with this dyad to secure resources through an NGO that was specifically set up to 'empower' women. Now, however, it is the women who feel they are giving their power to the organisation; their sense that their HIV is 'exploited' runs alongside a seemingly intractable tension in which the women perform their precarity and agree to 'get with capitalism' in order to continue

receiving orders for the paper mâché bowls from which they derive a crucial income for their household.

In this respect, this second character of the new generation struggles offers two perspectives on HIV, agency and performativity. First, it confirms the value of moving away from the 'problem/solution' framing of HIV and ARVs. This chapter shows that although HIV can be a form of embodied precarity, as explored in the previous chapter, it can also be a resource. The second related finding, then, is that HIV – as an actant within the body – can also be performatively mobilised 'outside' through economic relationships to manage precarity. In this regard, the women were able to strategically secure critical economic resources in a development milieu that perpetuates the 'gender/HIV' dyad. Second, the women's sense of exploitation indicates the limits to structuration theory (Giddens, 1990; Giddens, 1991) as they both strategically performed their precarity to secure resources, while at the same time feeling that their embodied precarity – their HIV – was a source of income, too, to the NGO that was exploiting their labour and their HIV-status. Therefore, both HIV and ARVs, as 'local biologies' (Bharadwaj, 2013; Gilbert, 2013) have not only influenced the kind of social relationships that people form, but they too have social lives that are differentially embodied in people's lives.

Given the dual character of these new generation struggles, the findings in this chapter iterate the importance of asking 'empirical questions' of the politics of life literature, and particularly the field of biosociality. While recognising the importance of sociality, this chapter also suggests that we might approach biology itself slightly differently to the way Rabinow and Rose characterised 'our biological century' (2006). Historically, Rabinow (1996) considered biology with respect to genetics, and Rose (2006) extended this approach to consider 'bio' with respect to biomedical technologies that could diagnose and treat genetic or other illnesses. Based on the findings of this chapter (and as I go on to discuss in Chapter Seven), I suggest that biosociality around HIV has shifted as the biology of the virus, too, has intra-acted with ARVs; this shift in the shape of HIV and its socialities has run alongside an emerging acknowledgement that ARVs, like HIV, also hold risk and are embodied as side effects alongside resumed health. The 'new generation struggles' discussed in this chapter are perhaps more difficult to address in public health programmes, and less amenable to pre-existing approaches to medicines as 'technologies of life', because they call attention to the complexity of medicines as they intra-act with HIV in individual bodies. They are further complicated, as I go on to explore in the following chapter, through shifting recollections of

illness and health as the people I worked with draw their memories of different times and spaces into the present through Anamnesis.

6. Embodied Topologies

This chapter is the metaphorical hinge around which the first and last two ethnographic chapters swing; it therefore not only moves out in scale from the intimate space of women's bodies to locate them in a network of topologies, but it engages with a set of theories that are particular to this chapter in order to articulate how assemblages take shape through shifting spaces, memories and social relationships. In this respect, it heeds Latour's (2004) and Collier's (2009) assertion that it not enough to simply assert the singularity of a network of actors, or the form they take in a global assemblage; instead, we need to understand the finely textured dynamics that animate actors in an assemblage, and, critically, we need to ensure the political resonance or broader applicability of our analysis.

The materiality of space, as it was held in women's memories and in their bodies, is the ethnographic focus of this chapter. It looks at how space and time shift into each other and are produced through women's dynamic recollections of their lives in the process of Anamnesis. This chapter therefore emerges from a genealogy of theory on space and reflects the importance of moving away from representationalist theories that separate nature and culture, technologies and bodies, citizens and the state, and physical and conceived space (Haraway, 1988; Haraway, 1997; Barnes, 2001; Butler, 2004b; Barad, 2007; Colls, 2007). Because these theories apply particularly to this chapter, they are outlined here and discussed in the ethnographic body below.

6.1. Thinking through Space

In conceiving space as simultaneously real and contested, Foucault's 1967 lecture on heterotopias (1986) heralded Lefebvre's (2006) analysis of the production of space. Suggesting that, "[W]e live inside a set of relations that delineates sites which are irreducible to one another" (Foucault and Miskowiec, 1986: 23), the authors speak to Lefebvre's (1991) subsequent work on heterotopy, and Latour and Serres's (1995) conversation on topologies in which they capture the notion that space is produced through sets of relations between its parts. With particular respect to science studies and the body, Latour (2004) argues that at the level of drawing together a collection of practices or observances, as I do here, we are in the active process of tracing power while simultaneously exerting it; further, he argues that the associative work, the actor network mapping, should be the focus of attention and not only

the forms – different types of power – that these associations can take (see also Nowotny, 2001; Latour, 2005). As I explore in this chapter, space and time, like power, emerge as a result of the kind of associations that bring heterogeneous elements into networks. In this vein, the term ‘topological’ represents the sense of,

space as being made out of relations between its parts... There are only fibrous webs gradually extending and contracting, erasing one another, copying one another and producing the shape of space and time in doing so. It is in this concern with how different assemblies of actants can connect up that Latourian spaces are often called ‘topological’ (Laurier, 2004: 438).

Historically, the concept of topology emerges from a trajectory of thought around the mathematics of space and, later, biology that can be traced back to as early as 1736, and the Greek-Latin Analysis situs, or ‘picking apart of a place’.

The relationship between topologies and health has been considered, for instance, in ethnographic research on the management of anaemia by tropical doctors. In their research, Mol and Law (1994) engage with the topology of bodies in conjunction with illness, narrative and networks through the metaphor of blood. They write, “Look at the person-patient-body sitting over there on that iron stool. Where is her blood? Is it in the lungs, in the legs, in the brain? Is it in the vessels, or isn’t it?” (1994: 642). The challenge, to the doctors, their clients, and the authors, lies in the solubility and fluidity of blood:

This much is clear by now: ‘blood disturbs the spatial securities of anatomy. It doesn’t fit... [I]f ‘anaemia’ unsettles spatial securities, then to talk about... it is to explore the topological presuppositions which frame the performance of social similarity and difference. Unlike anatomy, topology doesn’t localise objects in terms of a given set of coordinates. Instead, it articulates different rules for localising in a variety of coordinate systems... Topology, in short, extends the possibilities of mathematics far beyond its original Euclidian restrictions by articulating other spaces (1994: 643).

I use the term topologies to reflect the movement of actors and actants into the body, and in so doing, conceive of space as both fluid – like blood – and co-constructed through memory. While topologies indicate the processes in which actants, actors and time ‘come together’ and become embodied, I use the concept of Anamnesis to incorporate time as a further dimension in the embodiment of this assemblage. Specifically, I look at time as it is constructed through people’s recollections of illness and the search for healing, as these recollections, too, are located in fluid spaces.

Historically, the concept of Anamnesis was offered by Socrates in Plato's *Meno* to reflect iterations of knowledge or the ritual repetition of remembrance, and its contemporary inference is,

remembrance or reminiscence, the collection and re-collection of what has been lost, forgotten, or effaced. It is therefore a matter of the very old, of what has made us who we are. But Anamnesis is also a work that transforms its subject, always producing something new. To recollect the old, to produce the new: that is the task of Anamnesis (Harman, 2009: n.p.).

The task of Anamnesis thus implies a constant remaking of the present through processes of remembrance and recollection. Its contemporary definition indicates how, as a concept, it draws medical histories and narratives into the present through processes of recollection:

Anamnesis: /,anəm'ni:sis/

[mass noun]

- i. Recollection, especially of a supposed previous existence.
- ii. [count noun] Medicine, a patient's account of their medical history.²²

The task of Anamnesis, to remake the present through processes of remembrance and recollection, is pertinent in this chapter as these processes were knitted together in my fieldwork through dynamic narratives that expanded and contracted across space and time in networks linking viruses and medicines to memories and social relations.

In this vein, and linked to the role of narrative (re)construction in the task of Anamnesis, 'topological' has a biological inference that is salient for this chapter and relates to the medical anthropological facet of Anamnesis: that of the body. Anthropological approaches to narrative suggest that it serves to mediate between the inner world of thought and feeling and their expression and experience in the outer world. Reflections on the role of narrative in ethnographies, like Bohannon's (1966) account of co-constructing the meaning of Hamlet with Tiv men in West Africa, suggest the layering of stories that takes place as ethnographers make meaning of the meaning-making we observe and co-construct. In this chapter, Anamnesis is explored through a composite collection of narratives linked to women's memories as they (re)constructed their present through narrating their past. Iterating the medical dimension of Anamnesis as a patient's record of their medical history, the narratives explored here centre on women's recollections of embodied precarity linked to HIV and AIDS therapies in relation to the networks that draw these actants into their body, as discussed in the previous two chapters. This chapter moves out from the space of the body to locate these shifting narratives

²² <http://oxforddictionaries.com/definition/english/Anamnesis>. Retrieved July 2012.

in temporal and socio-spatial networks. In doing so, it demonstrates how these networks are threaded into the body and for this reason I describe them as ‘embodied topologies’.

The first section of this chapter dialogues closely with Chapters Four and Five and explores Anamnesis in relation to pathways that bring HIV and ARVs into women’s lives. By tracing women’s illness narratives across salient spaces and times, and along the lineages of social relations that stretch out before and after them, it considers the relationship between space-time and biopolitical precarity. The second section dialogues with Chapter Seven and Eight and explores activist networks across time by tracing memories of embodied precarity into the site of Khayelitsha as the space of political resistance in the struggle for democracy and then, later, in the struggle for ARVs. In sum, this chapter moves from the intimate space of the body to situate the body in a network of topologies that span the very old, the things that have made us who we are – rural ancestral homes, generational rites of passage – and the presence of historical spectres in the finely iterative generation of the contemporary politics of life.

6.2. Actants and Networks of Precarity

Chapter Four recounts Zama’s description of the lightning strikes that bring HIV into people’s lives, with the context for these ‘strikes’ - the skies that fight - explored along three pathways of precarity. These horizontal, vertical and diagonal pathways underscored the complex network of human and non-human actants that engendered precarity for women as they negotiated unequal gender dynamics, sex and intimacy, limited public health resources and stretched households straining under poverty and unemployment. In the course of tracing the routes that HIV and ARVs travelled to enter women’s bodies and lives, I came to understand that these pathways are temporal and socio-spatial, anchored in relationships and held in shifting memories of time and place.

6.2.1. An ‘Other’ Home: (Re)Constructing the Romance and Risk of the Eastern Cape`

The women I worked with painted the picture of their past, of their childhood home in the Eastern Cape, with narratives that layered over each other; the layers accrued over time, revealing shifting imaginaries of ‘home’ as simultaneously beloved and as other. This ‘other’ was not simply of ‘another’ place that was reconstructed through Anamnesis in order to journey back to the women’s previous lives, to places that had made them who they are, that had brought HIV into their body and ultimately precipitated their move away from home to

Khayelitsha. 'Home' was also an 'other' place that was held in place by the tension of two narrative strands, one of romance and the other of risk. These strands existed in relation to and because of each other, and it was through their juxtaposition that these strands became each other's 'other'.

Anamnesis of home as a place of romance reflects the conjunction of space and time as women traced the space of 'home' along the trajectory of their life: the Eastern Cape was narrated as the 'place of ancestors' where their life had started and where it would end. 'Home' was also the place where important rites of passage like weddings, circumcision rituals and funerals, took place to punctuate movement along this trajectory. Alongside the narrative of romance linked to the start and end of life and the rites of passage that marked the journey between birth and death, the women also described how life in the Eastern Cape became increasingly untenable as they entered adulthood. They spoke of home as a place of risk where gender inequality, poverty and unemployment, and poor health care and education coalesced into horizontal and vertical pathways of precarity. Further, it seemed that the shifting perspectives invoked through Anamnesis not only generated the simultaneous romanticisation and othering of 'home' in the Eastern Cape, but that these narratives were borne through the women's dynamic relationship to their current home and life in the adjacent Western Cape Province.

Encapsulating these tensions, Miriam said, "Cape Town's my home because it gave life to my child... I don't even want to tell you how small she was when we got here. But I want to die in the Eastern Cape because it is the home of my ancestors". We had spent the morning waiting in queues as Miriam went through a series of check-ups; on this particular visit they extended beyond the usual monthly blood pressure and weight checks and included the more detailed tests to make sure that her ARVs (a combination of aluvia, 3TC and tenofovir) were not having adverse affects on her body. Miriam felt that the medicines were having seriously negative effects on her body; she said that aluvia, in particular, was responsible for her chronic backache and what was termed by her doctors as 'morbid obesity'. According to Miriam, these effects were not taken seriously by the nurses and doctors and instead, she felt blamed for these conditions rather than supported in addressing them. On this visit she had resolved to speak to the nurse and "finally be taken seriously". The nurse had told her, again, that the biomedical markers of her health – her CD4 count, viral load and blood pressure in particular, according to Miriam – indicated that the medicines were "doing their job" and Miriam was advised to go on a stringent diet. Miriam therefore left the clinic with her medicines, feeling

resentful that she had not been taken seriously despite mustering the courage to query the efficacy and effects they had on her body. Despite her ambiguous relationship with her ARVs and the health care practitioners that administered her treatment, it was as we were driving out from the clinic that Miriam spoke of her longing for the Eastern Cape alongside her resolution to remain in the Western Cape because it was the 'home' of ARVs, the place that facilitated her and her child's contingent capacity to live.

The women's narrative reconstruction of the Eastern Cape as 'other' shifted across the course of my fieldwork, suggesting that these narratives were not rooted in space, as Haraway (1988) suggests, but instead were fluid and co-constructed with space-time through the process of Anamnesis. Frequently, when speaking against Khayelitsha and her struggle with living on the cusp of poverty as her household's sole income earner, Miriam would move to reminiscing about her life in the Eastern Cape. In the absence of photographs, she drew pictures in her diary and through our conversations of the lush green valleys that she grew up knowing as intimately as she knew the layered histories of the handful of families that lived in homesteads dotted along the hilly ridge where her family, too, had a home. Miriam associated this home - her birth-home - with her mother and the lineages of ancestors that preceded her; it was here that she would, if she could, return to die. Alongside these nostalgic narratives of 'home', when describing the factors that had led her to seek medical treatment in the Western Cape, Miriam spoke of the strain she struggled under as a young girl in the Eastern Cape and the myriad factors that had coalesced to bring HIV into her body. I reflect on the illness and therapeutic narratives that Miriam recounted through Anamnesis here as they point, more broadly, to the factors that engendered precarity for the women with whom I worked (linked to illness narratives), and the reasons (linked to treatment narratives) they left the Eastern Cape in order to secure life-saving medicines in the Western Cape.

Miriam grew up with her mother and two younger brothers in a small home: a single round room circumscribed by mud walls and covered by a thatch roof that sheltered them from rain but not from the extreme heat and cold of the shifting seasons. They did not have running water or electricity and she and her mother spent two hours each day walking along the contour path that wound along the hills between their blue-painted home and the nearest river: their sole source of water. Her mother was chronically ill and their household's only source of income was her mother's disability grant; occasionally, when they ran out of money, their neighbours would share the few vegetables that they could spare or help Miriam collect water when her mother was unable to make the journey herself. Miriam said that this

(somewhat strained) benevolence ended when their neighbours learnt that her mother had had a relationship with a married man living in the adjacent village; this man was the father of Miriam's two brothers. Like Miriam's own father, he did not provide any form of support to Miriam's mother. This, she explained, was, "[Because] men think it's fine. They just want women women women. They don't care about the children... Me? Hm! I don't care anymore about my father."

In Chapter Four, I describe how Miriam had entered her first sexual relationship after she was compelled to return home from Mthatha, where she stayed with her uncle to attend high school, in order to care for her dying mother and her young brothers. Miriam spoke angrily about the way that men in her family – her father, her brothers' father and her uncle in particular – eschewed responsibility for caring for her mother when she became ill. The flip side to this negation of responsibility is the apparent assumption that as a woman, Miriam was expected to leave high school three months before writing her final high school 'Matriculation' exams in order to care for her mother. Miriam did not question caring for her mother, but she was deeply resentful that her education came at the cost of this care.

Miriam wrote in her diary about how her mother had become slowly, irrevocably, incapacitated because she had been poisoned through witchcraft by the wife of the man who had fathered Miriam's two brothers. Following her mother's death, at the age of 17, Miriam became the head of their household, caring for her newborn and extremely ill daughter and her mother's two children. She wrote about this time as being "the darkest" of her life. Without any financial support (her household could no longer draw on their mother's disability grant), she and her brothers struggled to eat as her child battled to live in the clinic; at a loss, she chose to move with her daughter to the Western Cape in order to access health care resources that would come to save her child's life.

Miriam refused to have sex with men when she was in high school, where she had excelled, because her education was her priority and she did not want to become pregnant; looking back at this time of her life, Miriam described her dream of becoming a teacher – a dream inspired by her own teachers in high school. However, when this dreamt possibility was no longer a potential reality, Miriam 'made do' in De Certeau's (1984) terms by navigating the imperative of taking care of her mother with very few resources as strategically as she could. In part, her decision to enter a sexual relationship with Luyokiso was prompted by Miriam's feeling that "he was the only one caring for me". In the absence of all other forms of care

Miriam did not feel that she could negotiate the frequency of their sexual contact. Further, without knowledge about HIV or other sexually transmitted diseases, or information about sex more generally, her relationship with Luyokiso was characterised by painful and unprotected sex. She described her partial relief when hearing that Luyokiso was also having sex with other women in the neighbouring village; she said that this gave her a legitimate reason to end their relationship and, within a few weeks, entered another relationship with Mandisa, whom she came to love and who, later, became the father of her first child, Nena. Miriam said that she contracted HIV from Luyokiso because a few months after their relationship ended he had become seriously ill and subsequently died; she believed that he died of AIDS.

6.2.2. Pathways of Precarity and the Socio-Spatial Generation of Gender

The gendered expectations of care that compelled Miriam to leave high school prematurely and, going back further, placed sole responsibility on Miriam's mother to care for her children were, according to the women I worked with, inculcated through rites of passage that took place in the space of the Eastern Cape. The Eastern Cape was (re)constructed through Anamnesis, and the partial perspectives invoked through the juxtaposition of romance and risk, as the socio-spatial repository of isiXhosa cultural knowledge that was transmitted across generations through rites of passage that include circumcision, marriage ceremonies and funerals. This section explores the tension between, on the one hand, the women's assertion of the importance of kinship and, on the other hand, their struggle with the implicit and, at times, explicit socialisation of gender roles through these same practices that reinforce kinship ties. I look at one particular practice – male circumcision – because of its salience in the narratives of the women with whom I worked as a rite of passage that strongly conditions unequal gender relations and that, therefore, was a factor that enabled HIV to move along horizontal pathways into women's bodies. Rather than reinforcing a static notion of 'male' gender, we see how circumcision quite fundamentally illustrates the performative construction of gender and therefore its fluidity. In thinking about gender performatively, it is also possible to see how the women I worked with navigated the kinds of gendered expectations that spiral out from this practice and its shifting epistemological underpinnings. This reflects Butler's assertion that gender is not an essential identity but a shifting construction generated by performance (1988). She comments on Simone de Beauvoir's claim that, "One is not born, but rather, becomes a woman", saying "gender is in no way a stable identity or locus of agency from which various acts proceed; rather it is an identity tenuously constituted in time... instituted through stylised repetition of acts" (1988: 519). Butler's (1988)

observations about the performative acts entailed in 'becoming women' also apply to the brothers, fathers and sons of the women I worked with as they 'became men' by undergoing circumcision (and very many other ways that I cannot detail here).

The public health discourse of circumcision was a strong feature in my conversations with activists during my fieldwork, particularly given that part of my fieldwork entailed working with TAC and writing articles linked to key areas identified for policy advocacy. As it is termed in the public health domain, male medical circumcision (MMC) has been lauded as an effective intervention for reducing the risk of horizontal transmission of HIV from women to men. Circumcision was a salient topic during my fieldwork because clinical trials conducted in Uganda, Kenya and South Africa estimated that circumcision afforded men up to 61% protection from transmission (Auvert, Taljaard, Lagarde, Sobngwi-Tambekou, Sitta and Puren, 2005; Sawires, Dworkin, Fiamma, Peacock, Szekeres and Coates, 2007). However, anthropologists and other social scientists have pointed to a set of social dynamics that complicate the simple application of this WHO policy directive. These include contestation over the rights to implement the practice asserted by traditional leaders and implications of male circumcision for women's health (Hankins, 2007; Meissner and Buso, 2007; Vincent, 2008). Louise Vincent, for example argues that, "[M]ale circumcision rites need to be understood within a highly complex contemporary socio-sexual context that is shot through with themes of violence, familial breakdown, resource scarcity and inter-generational conflict" (2008: 432).

The purpose of this sub-section is not to reflect on the larger social and policy dynamics linked to circumcision. Instead, it points to the relationship between the space of the Eastern Cape, the timing of this rite of passage, and specific local cultural practices linked to circumcision. This topology of time, space and cultural practice may, through performance in which particular kinds of masculinity are sanctioned, reinforce unequal gender relations. These unequal relations, in turn, may engender embodied precarity for both men and women through the performative construction of masculinity linked to unprotected sex and sexual concurrency.

At the start of my fieldwork in 2010, many of the women I worked with were preparing to journey back along the N2 highway out of the Western Cape to their homes in the Eastern Cape to celebrate Christmas with their families. December is also a time of year marked by the flow of boys on the cusp of manhood as they travel to the Eastern Cape to undergo traditional

male circumcision 'in the bush' (a reference to the oblique space in which this practice, shrouded in mystery for women, takes place). Miriam had, in the course of 2010, carefully saved up the large amount of money required to send her 23-year-old brother, Masiphiwe, back 'home' to be circumcised in December; and Yvonne, at the same time, travelled to her birth-home and also to her partner's home in the Eastern Cape to celebrate his brother's return 'from the bush'. Prior to travelling home, Yvonne spent weeks wondering whether or not to go with her partner to welcome his brother back 'from the bush'. She was concerned that she would be corralled into performing the role of 'wife' and given onerous responsibilities like participating in cooking for the fifty family members who would celebrate the conclusion of the circumcision ceremony with a feast. In the excerpt below, she reflects on the way women are expected to perform deference to men when they become 'wives':

Although we're not married, they still expect me to be the wife. It's like a compliment, almost. They want to treat me like a daughter... But also, they want me to behave like a wife. To be silent; to take care of their son; to only be with other [married] women who wear shweshwe. I couldn't have friends who wear trousers [laughing and pointing to me], like you, you know (Yvonne, 2011).

When she came back from the Eastern Cape in January 2011, Yvonne spoke of her relief in returning to the life that she had built in Khayelitsha with her mother and her son, a life where she was not primarily identified as a partner or wife. Yvonne's decision to eschew marriage is explored in detail in Chapter Four as a strategy for managing the narrow gender roles that are sewn into place through rites of passage like circumcision and marriage that are strongly associated, through Anamnesis, with the space of the Eastern Cape. Her equivocation about travelling back to the Eastern Cape with her partner, therefore, was perhaps a way that Yvonne was able to navigate these kinds of gendered expectations across the two spaces that she inhabited – in Khayelitsha, where she managed her independence by living in a separate home from her partner, and in the Eastern Cape, where she was, also, proud to be associated with her partner and some of the cultural performances and practices that took place in this space.

In their accounts of this rite of passage, Yvonne and Miriam moved between describing the place of the Eastern Cape romantically, on the one hand, as the socio-spatial repository of important cultural knowledge that was becoming eroded through linked processes of urbanisation and modernisation in peri-urban areas like Khayelitsha; and on the other hand, they described the Eastern Cape as the place where, because of these cultural practices, men

were compelled to perform particular kinds of masculinities that, in turn, correlated with expectations for how women should defer to the authority of men in social and sexual relationships, thus engendering vulnerability linked to the horizontal pathways of precarity described in Chapter Four.

The narratives of romance and risk that accreted in Miriam's recollections of home intersected with her reflections on her brother's recent circumcision in December 2010. As a form of Anamnesis, this account drew in multiple shifting narrative strands. I met Masiphiwe just as he had returned 'from the bush' in the Eastern Cape; initially he wore a traditional blanket around his shoulders, and did not make eye contact with me or Miriam, or any women, as per the instructions he had received during his initiation. After a month, he stopped wearing the traditional blanket but continued, despite the hot weather, to wear long pants, a button-up shirt, toe-capped shoes and a cap shielding his eyes. Miriam said that Masiphiwe's circumcision, although extremely expensive, had been valuable in bringing their father's brother back into their lives. Masiphiwe's father, as described above, had not played a role in his children's lives; as such, Miriam's mother and her mother's family were important figures in Miriam's account of growing up in the Eastern Cape. Although Miriam was pleased to feel that the responsibility for bringing her brothers into adulthood was shared, albeit very briefly, with her uncle, she was also concerned that the gendered expectations her uncle held were at odds with Miriam's insistence on equal responsibility between her brothers and herself in their care for their shared home in Khayelitsha.

Her concerns were borne out as Masiphiwe insisted on sharing Miriam's home, but refused to collect water, pay for any food, or clean and wash their home when he returned from his circumcision. Expressing a similar ambivalence towards circumcision, Zama said that she would make sure her six-year-old son, Lwazi, was circumcised when he was 18 years old because it was vital for his entry into adulthood, but that she would ensure that in the intervening years he learnt, by watching her live her life, that women were strong and deserving of respect. This rationale underpinned her decision to end her relationship with Lwazi's abusive father; she was concerned that her son would learn, through observing his father's abuse, to disrespect women. She was therefore resigned to the importance of circumcision as a rite of passage while also deeply suspicious about this rite as tool used by men to transmit discriminatory constructions of gender hierarchies that place men at the pinnacle under the guise of 'tradition'.

The women's accounts of isiXhosa cultural practices were ambivalent, sometimes shifting to reflect their sense that cultural practices like circumcision shaped particular forms of masculinities that infused gender relations and fuelled the transmission of HIV along horizontal pathways. At other times women expressed a commitment to 'culture' as held in the place of the Eastern Cape through practices like circumcision, and as indicated by the accounts above in which the women indicated their ambivalent commitment to ensuring their brothers and sons underwent circumcision. Similarly, while resenting and attempting to resist the expectations that were placed on her as a woman, Yvonne also shared a series of films that, she said, "Made me proud of my culture," thus tipping away from the partial perspective of the Eastern Cape as a place that inculcated unequal gender relations towards an romantic reminiscence of Eastern Cape as the place of 'culture'.

One of the most notable films was of a group of men as they moved quickly down the hill just beyond the collection of mud and grass homes that belonged to Bheki's family. As she clicked 'play', Yvonne pointed to Bheki as he led a group of about 20 men down the hill, dancing and gesturing with a large white stick. He appeared both protective of and aggressive towards his brother who, wrapped in a large blanket, his face covered with white paint, walked at the centre of this group. This stick fighting ceremony served two purposes according to Yvonne. First, it marked the integration of Bheki's brother into the generation of men who had been circumcised before him as they, together, entered the family's homestead. Second, it symbolised the attributes of men – particularly virility and strength - that the initiates were expected to embody as an outcome of the circumcision process. Yvonne decried the expectations placed on women to be passive and silent in relationships, and attributed these expectations to cultural practices like circumcision, but when commenting on the stick fighting ceremony, her eyes came alive and she said,

See how handsome he is? You know, this circumcision is important for us [isiXhosa-speaking people]. It's difficult to do our culture properly in Cape Town because we don't have the mountains here. Where do the boys go here? Eh! To those camps next to Lookout Hill [in Khayelitsha]... Sometimes bad things happen there and the boys try and run away. This is why it's better in the Eastern Cape (Yvonne, 2011).

Although there was no question about the importance of this rite of passage, the women's accounts indicated a concern about the information the older men communicated to the younger generation through the lessons 'in the bush'. Women were not able to access information about the specific practices that form part of this rite, but their narratives suggest

that the socialisation that takes place in the hidden space of ‘the bush’ has negative implications for women not only in terms of sharing responsibilities in the household, but also in terms of gendered expectations linked to unsafe sex, sexual violence and multiple concurrent sexual partnerships. The women I worked with recounted a number of instances where men in their lives – relatives and partners – had marked the completion of their transition to adulthood by having unprotected sex with a woman who was not their partner when they returned from the Eastern Cape.

In line with Butler’s (1988) theory of gender as performative, rather than essential, studies conducted in South Africa suggest, too, that ‘going to the bush’ for circumcision is a critical space for gender and sexual socialization. Wood and Jewkes (1998), for example, researched the circumstances and contexts of violence in young people’s sexual relationships. They found that men view sex as their right, believed that forced sex was legitimate, and that older men – including male teachers who had sex with female students – conveyed to younger men that all girls are ‘fair game’ and that masculinity was measured largely through the number of sexual partners men had and their ability to control their sexual partners. These findings have been iterated through subsequent studies with a larger cohort of men across South Africa (Auvert *et al.*, 2005; Sawires *et al.*, 2007).

The othering of ‘home’ surfaced through the women’s illness narratives as they made sense, through Anamnesis, of the things that had made them who they were, of the factors that had engendered their precarity and enabled HIV to enter their bodies. The Eastern Cape was narrated as risky in relation to the topology of this place as one that engendered precarity and enabled HIV to move along pathways into women’s bodies in two ways. First, through the narrative construction of the Eastern Cape as a socio-spatial repository of cultural practices that reinforced gender inequality and powerfully shaped social relations through rites of passage, like male circumcision. Second, the absence of the state was felt by the women in the dearth of public health care centres and resources. As discussed in Chapter Four, most of the women I worked with learnt that they were HIV-positive in the late 1990s and early 2000s, at a time when the government refused to provide AIDS therapies, including PMTCT. The presence of MSF’s ARV trial in Khayelitsha was therefore an important aspect of the women’s narrative recollections of Khayelitsha as a life-giving space. This partial perspective of Khayelitsha, in contrast to the Eastern Cape, as a first place that ‘gave life’ through MSF’s provision of ARVs also fuelled the othering of the Eastern Cape. These two spaces (of ‘home’ in the Eastern Cape and in Khayelitsha in the Western Cape) danced along a narrative seesaw, counterpoints to

each other: pathways enabling HIV to enter the women's bodies were attributed to topologies of 'home' in the Eastern Cape; and pathways enabling AIDS therapies to enter women's bodies were attributed to topologies of Khayelitsha. This seesaw shifted again, as the contextual struggles around life (particularly housing, education and employment) in Khayelitsha became salient and were positioned against a nostalgic reminiscence of 'home' as the place of green open spaces, spacious homes and strong social networks.

6.2.3. The Memory of Illness in the 'Brown map' of Skin

As discussed above, the space of the Eastern Cape was (re)constructed through layered narratives of romance and risk; these accounts were also fluid and partial, depending on the point at which they were invoked through Anamnesis in the course of my fieldwork, and also depending on where the women were situated in space-time between the Eastern and Western Cape. Zama, for example, travelled along the N2 highway back 'home' in December 2010 to be with her sister's family for Christmas. Prior to her departure, she described 'home' as a place with 'green-smelling air'; she spoke of the river that she swam in and that she, her mother and sisters, would use for their household's cooking and cleaning. When we spoke over the phone at Christmas, I heard how much she had missed her sister and how wonderful it was for her to be in a place where she could watch her son playing outside with his cousins, not fearful of the live electricity wires that hung over his head in their garden in Mfuleni.

When Zama returned, she took me on her journey by taking me through the photographs she had taken of her trip home. After a series of photographs taken at night to mark the stops along the N2 highway, we moved into daylight and a photograph taken out of the window of the minibus taxi she was travelling on with her son, and a friend's child of the same age. The photograph was of a green open space, dotted with trees, against a sloping hill. "Here is our toilet," she said. The next photograph was of about 100 pastel-painted Reconstruction and Development Programme (RDP) houses. Looking at me with a wry smile, Zama explained that,

Nothing works in these houses. The government wanted to look like they were doing something good for us. But they just built us walls. Like empty shells. They stopped with the pipes. [Laughing] Sisi, you would not like this. It's not like here where my toilet works (Zama, 2011).

Gloria lived in one of these pastel RDP houses with her children and her partner, and it was here that Zama was based with Lwazi for Christmas. Zama said that she used a bucket at nighttime, instead of leaving the safety of their home, because she had heard that women had

recently been raped when they had gone out at night to the open place that functioned as the community's toilet space. This narrative contrasts with her account, prior to her trip, of home as a place of safety, and of green open spaces as indicative of the romance of the hills and valleys of the Eastern Cape, rather than of the incomplete construction of the RDP homes in this impoverished region.

A few days into her trip, Zama, Gloria and their children travelled to their father's plot up in the valley; a few years previously her father had sought permission from the village chief to build a home. The home reflects her parents' wish to move from their small shack in Khayelitsha to the larger space of Engcobo, but the reality of the remote rural location has meant that Zama's father was forced to stop the construction on his home. The house still stood on the land, half built, with mud and grass meshed into the trees that had been stripped and tied together to form walls. Tilled earth, also ringed by a fence of trimmed tree-trunks, was a visible reminder of another history. In 2003, Zama's brother, Sihle, had become frustrated with his life in Khayelitsha and decided to return to his father's land in order to try to make this home his own. Sihle was frustrated, as Zama recounted, with "The concrete buildings everywhere and the bad air," and so he sought a referral letter from the MSF clinic, where he received his ARVs, in order to relocate to his family's home in the Eastern Cape.

On his return, he continued to build the home and to grow vegetables in the vegetable plot; Zama had taken a photograph of this plot, with its faint history of hardened ruts and tilled soil. Given the scarcity of clinics in the Eastern Cape, and the complete absence of ARVs through the public health sector throughout South Africa in 2003, Sihle needed to travel to Lusikisiki each month to get his ARVs; Lusikisiki was the only place, aside from Khayelitsha, that provided ARVs through MSF at that time in South Africa's history. Unable to afford the cost of the return taxi journey to Lusikisiki from his home high up in the mountains, about three hours away, Sihle stopped taking ARVs. He became very sick very quickly in the course of a month and, financial cost aside, was too frail to attempt the journey to the clinic to access his ARVs.

Sihle's father travelled back to their home in the Eastern Cape to bring Sihle to Khayelitsha. Also extremely frail, he carried Sihle on his back and then in a wheelbarrow along winding routes down the mountain, over almost impassable mud roads. When they reached the larger tar road they were able to get into a minibus taxi and start the slow, long journey back along the N2 highway to their other home in Khayelitsha.

Sihle's account suggests a topology that draws multiple factors into his experience of illness and of healing linked to time-space. He was able to access medicines to sustain his life by living in the geographic space of Khayelitsha at the time the MSF trial started; but despite experiencing resumed physiological health, he felt that living in Khayelitsha came at the cost of his wellbeing. However, the place of home, high in the mountains in the Eastern Cape, and the dearth of public health care resources and the relative absence of AIDS therapies through the public sector in 2003, meant that it was very difficult to sustain his health. The space of the Eastern Cape, when joined with the time of 2003, reflect a topology in which this space-time enabled HIV to replicate in his body and, also, to develop resistance to the first line treatment regimen that Sihle had been receiving in, and that prompted his return to, Khayelitsha.

Moving with Zama's illness narratives, we travelled between her memories of Khayelitsha and her family's home, the Eastern Cape, as her narrative recollections of first becoming ill overlaid each other, each becoming more or less salient through Anamnesis. In the conversation we had about the skies that fight, the lightning strikes that bring HIV in women's lives and bodies, Zama had gone on to say,

In the Eastern Cape we used to believe that the witchdoctors made the lightning. We would watch from inside our homes to see if anyone came out in the storm to speak to the skies. If they did, we would know it was them. They were making the skies fight.

Sometimes people did go out, but looking back, they were just crazy (Zama, 2010).

When Zama first became very seriously ill in 1999, she sought treatment with an *isangoma* (traditional healer), believing that her illness had been caused by the kind of witchdoctor that made the skies fight. Her illness was embodied as drastic weight loss, chronic joint pain, difficulty in breathing and a painful skin condition. The *isangoma* confirmed her suspicion of witchcraft, saying that she had been bewitched to be a snake because her neighbours were jealous of her education and ability to seek skilled employment. At the time Zama became ill, she had just completed training to be a security guard and had been working as a petrol attendant in the Western Cape. Her illness had made it difficult to continue working, and she had returned, like many of the women I worked with, to the Eastern Cape to be cared for by her extended family.

The narrative of witchcraft, told to her by the *isangoma* and affirmed by her family, made sense to Zama for a number of reasons. Alongside this sense-making, which I turn to below, Zama was latently aware that she may be HIV-positive – an aetiology that also made a degree of sense, but that was significantly more frightening in the absence of ARVs and in the

presence of vicious stigma borne through misinformation. This shifting process of sense-making, through Anamnesis, points to multiple intersecting conceptions of illness and the sedimentation of narratives that accompany this sense-making of bodies that become frail in the search for healing.

The quieter narrative of HIV was layered into her belief that she had been bewitched for two reasons: one, because Sihle, whom we met earlier in the chapter, had experienced a similar set of illnesses in quick succession in Khayelitsha a few months previously and had tested HIV-positive; two, because she had been told by the sister of a previous partner, with whom she had had unprotected sex, that he was HIV-positive. Perhaps, rather than distinguishing between the two strands of narratives, as one might if trying to make sense of Zama's sense-making from the outside, we can see that, for Zama, these strands are layered into each other through Anamnesis. There were times when Zama spoke of being bewitched to be HIV-positive. In this respect, anamnesis extends the historical medical anthropological approach to illness narratives developed by Kleinman (1989; 1994) because it moves away from linear narrative accounts to recognising how we constantly reconstitute ourselves through shifting recollections of our past, where the things that have made us who we are, that have in some cases made us ill, also shift over time and space and come to be layered into each other. Further, the critique of representationalism held in Haraway's (1991) account of material-semiotics suggests value in moving beyond binaries in which Zama's account of illness is either material (linked to the presence of the virus in her body) or semiotic (linked to witchdoctors that make the skies fight and engender illness). The value of material-semiotics, as I discuss in the previous chapters by exploring the intra-action of HIV and ARVs as actants with(in) the body, lies in the scope it offers for engaging in the far muddier and perhaps more ontologically accurate space between the poles that separate mind/body, materiality/semiotics, citizen/state, body/technology – to name a few. Zama's account suggests that her experience of embodied illness lies in the space between materiality and semiotics, shifting and settling over time and in different spaces.

Through an iterative sedimentation of illness narratives, Zama related the multiple beliefs she held to make sense of her body's illness and, in the conversation we had around the skies that fight, she explained that she simultaneously questioned and wanted to believe that the witchdoctors had made the skies fight. Her assertion that, "[L]ooking back, they were just crazy," reflects the layering of beliefs and disbeliefs over each other at different space-times. At the time that Zama became ill, ARVs were not available in South Africa; therefore

biomedical treatment was not a viable option. Traditional healing, on the other hand, made sense for Zama at this time because it was a healing strategy that she understood and that conferred a degree of control to her in a situation that had otherwise felt utterly perplexing. In 2010, talking about this time retrospectively, Zama reflected on the role of the TAC's treatment literacy campaign, and her role with TAC as an activist and educator since 2001. Through her engagement with TAC, Zama had learnt about the science of HIV and had fought for her right to access ARVs; therefore, looking back in time to her younger self, she reasoned that, in fact, the witchdoctors did not make the skies fight, and that they were also not responsible for making illness enter people's bodies – and that this belief was, in fact, crazy. In course of 'sense-making' through Anamnesis, Zama made sense of her decision to see an *isangoma* because she wanted to locate the responsibility for her illness with social ill will between herself and her neighbours; thus also affirming her relative success rather than foregrounding her dismay at her shedding skin and inexplicably ill body. Therefore, at that particular space-time, the narrative of bewitchment was most salient because the narrative of HIV was far more daunting and at that time and in that place, without ARVs, impossible to heal. Zama's narrative also reflects another limitation to representationalism's insistence on binaries. Her account, as recounted through Anamnesis, suggests that there is not necessarily a clear distinction between biomedical care and traditional healing in South Africa; instead, a plurality of health care approaches exist alongside each other, sometimes moving into and reinforcing each other at different junctures of space-time (see Shuster et al, 2009; Peltzer et al, 2006; Wreford, 2005).

The memory of this time in her life is visible as a form of embodied Anamnesis in Zama's skin. The *isangoma's* explanation for Zama's illness, namely that she had been bewitched to be a snake, resonated because of the condition of her skin at that time, a condition that had made parts of her skin go grey and dark in colour against the lighter brown of her skin. Almost absently touching my wrist as we were talking, Zama pulled her long sleeves up over her forearm and then pointed to the trousers covering her legs; over a decade later, the effect of illness was still evident in the tiny dark circles that moved up and down her skin, the skin she describes as a 'brown map'. Looking back to the time when she was very sick, as told through the story of this 'brown map', Zama said that her skin was akin to that of a snake: hard imbrications of flakey skin that reminded her of the "supposed to be soft but really rough skin" that snakes shed as they grow.

Her memory of becoming very seriously ill also connects to the space of home at a time when

she initially sought treatment for being bewitched with an *isangoma*; she describes the space of her home as one where HIV was unknown, and where traditional health practitioners were the primary providers of care to ill people. This space connects with the time that Zama became ill, and the dearth of information around HIV prevention and complete absence of treatment in South Africa's public health system in 1999. Zama's description of her skin as a 'brown map' iterates the intersection of space and time; a space-time that her body bears witness to through the fine circles that, although lighter, still lie on her skin. This form of embodied Anamnesis, retold through layered illness narratives and visually held in her skin, not only draws time and space together, but also indicates how the past is held in the present in Zama's body.

Zama was cared for by the *isangoma* over a number of weeks following a ceremony, also referred to by Zama as having taken place 'in the bush', during which time the *isangoma* slaughtered a chicken, mixed the chicken's blood with brandy, and rubbed this mixture into incisions she had made in Zama's skin. Zama's health improved slightly, but then declined very rapidly. A few months after Zama's treatment with the *isangoma*, Sihle joined the MSF trial in Khayelitsha. As she became increasingly ill, her brother became insistent that she travel back to Cape Town to be tested for HIV and to start ARVs through the trial. At this time, Zama was aware of the then-President Mbeki's equivocation on the efficacy of ARVs, and was concerned that even if she was HIV-positive, she would die from the ARVs because they were toxic. Holding her hands in the air, as though she was balancing scales, she said,

I could see that I was going to die anyway; so I thought I may as well try the ARVs. If they kill me, then at least I would have tried everything. But a part of me thought they may actually save my life. And now look at me. I'm still here. On the same treatment as then. Except now I have my beautiful boy (Zama, 2011).

Like all the women I worked with, Zama's treatment narratives entail travelling 'home' to the Eastern Cape to receive care when she became very sick and then moving back to the Western Cape to receive biomedical care in order to survive. This indicates a broader issue around the space of the Eastern Cape and the relative dearth of health care in rural regions of South Africa. As discussed in Chapters Four and Five, access to health resources – like information about HIV, condoms, ARVs – was limited to small clinics dotted across the region. The absence of resources, I argue in these chapters, were factors in the generation of precarity along horizontal pathways as women entered sexual relationships in the Eastern Cape, unaware of HIV, and unable to negotiate sex, or safe sex, to the extent that they would have liked when looking back at this time in their lives.

Further, as discussed in Chapter Four, the spatialisation of health care resources alongside the government's failure to provide PMTCT through the public health system also enabled HIV to move along vertical pathways, through umbilical cords and breast milk, from mothers to their babies. Miriam, Lilian, Thandiswa and Brenda all gave birth to a child in the 'window period' when the HIV epidemic was escalating in the late 1990s and before the government provided AIDS medicines to halt the progression of HIV and to prevent vertical transmission. According to the women's recollections of life in the Eastern Cape, and as illustrated in the map below, the state's presence, embodied by public health clinics in this instance, was far removed from the small villages that most of the women lived in. Consequently, without access to PMTCT, these women gave birth to children who became seriously ill and, in the case of Brenda, Thandiswa and Lilian, subsequently died. Miriam's daughter, too, was born on the cusp of death, severely and unintelligibly ill. Recognising that her daughter's life was contingent on finding medical support that could decipher and treat her illness, Miriam moved to live with her partner in Khayelitsha. Here, she accessed care for her child and learnt that she and her child's father were HIV-positive. Because she was located in the catchment area of the MSF trial in Khayelitsha, Miriam was able to access essential biomedical resources that enabled both her and her child to live.

Sihle's account above illustrates the relationship between space-time and embodied precarity when living in remote regions of the country where public health resources, like AIDS therapies, are either not available, or scarcely distributed and difficult to access. The greater density of clinics in urban areas compared to rural areas prompted the South African government, at the time of my fieldwork, to develop a national policy on Community Health Workers (CHWs) as a strategy to ensure that people in remote areas can access health care. The logic for working with CHWs, and ensuring their integration into a national public works program, lies in CHWs ability to access hard-to-reach places and provide lay health care and resources to people in these areas (Jewkes *et al.*, 2009; Jewkes *et al.*, 2010; Jewkes *et al.*, 2011). In order to lobby for the integration of CHWs into the national public works program, and to provide information on the nature of the CHW policy, we developed an Equal Treatment Issue with a focus on CHWs. In this issue we visually tracked the story of a woman's journey to access ARVs in the Eastern Cape in order to demonstrate the multiple costs entailed in accessing health care for people living in remote regions of South Africa. Her story is illustrated in the digital map below.

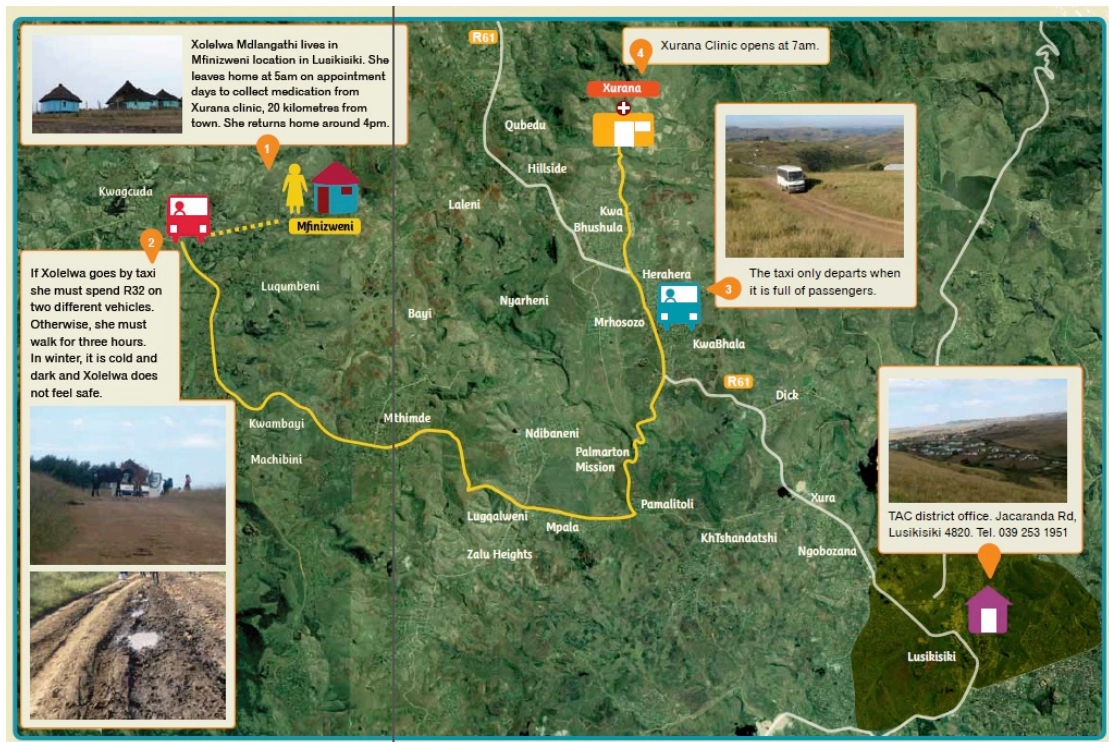


Figure 6.1. Digital map of Xolelwa's journey to her clinic in the Eastern Cape (Source: Equal Treatment, 2011)

Using Google Earth's drop down markers, we tracked Xolelwa's journey from her home (point 1) to her clinic (point 4). The image on the top left hand corner is a photograph of Xolelwa's house in the Mfinizweni location in Lusikisiki in the Eastern Cape. She, like the majority of the women I worked with in Cape Town, was required to attend her clinic on a monthly basis in order to receive her ARVs. The closest clinic in the Lusikisiki catchment area was the Xurana Clinic, 20 kilometres away from her home. In order to reach the clinic, she wakes up at 5am and walks to catch a taxi in the neighbouring region of Kwagcuda. The taxi takes her across from Kwagcuda to Herahera, where she then moves over into a second taxi. The taxis in both places wait until they have the maximum number of people before leaving and this can entail long periods of waiting, particularly early in the morning. The cost of a return taxi ride from Xolelwa's home to the clinic is R32 and there are times when Xolelwa cannot afford to pay for her transport. The research I conducted for the previous issue of ET on Drug Resistance indicated that the cost of transport to and from clinics was one of the major factors that undermined adherence to ARVs: people who cannot afford to travel to the clinic, and who may be too ill to walk a long distance, are unable to access their treatment. In Xolelwa's case, when she could not afford to travel with a taxi she would walk three hours to get to and from the clinic. This was particularly problematic in winter when it was dark and cold in the early mornings and evenings. In addition to the risks posed by the weather, Xolelwa was concerned

about being vulnerable to crime, particularly rape, when walking to the clinic from her home. As indicated through Sihle's account, a vicious cycle ensues as people stop taking ARVs because it is too costly or risky to travel to the clinic: they become ill and possibly develop drug resistant strains of HIV at which stage, even if the person is able to access medicines – through the assistance of CHWs for example – the treatment may no longer be effective.

This map reflects a particular landscape of health care in the Lusikisiki region in the Eastern Cape in 2011; a decade previously, in 2001, many of the women I worked with encountered a similar landscape of limited health care resources that formed part of a broader topology that brought HIV into their own and their children's bodies through vertical and horizontal pathways. The 'othering' of the Eastern Cape as a place of risk was particularly salient in the women's accounts of the pathways that brought HIV into their bodies, and into their children's bodies. These accounts, in turn, constructed the space of Khayelitsha as 'life-giving' due to the MSF trial that they were able to join at a time when most AIDS-sick people were dying in South Africa due to the government's obdurate refusal to provide ARVs. The provision of AIDS biomedicines through the MSF trial in Khayelitsha indicates a particular topology that brought together people who actively moved to this location from the Eastern Cape and non-governmental organisations like MSF, that worked to limit the effect of HIV and enable the capacity of people, like Miriam and her daughter, to live. Just as the space within the geographic boundaries enabled Miriam to access essential medicines to support life, it excluded many more people and like a litmus test, highlighted the radical ramifications of the government's failure to provide these medicines across the country through the public health system. The section below moves back along the N2 into the space of the Western Cape and the Cape Flats in particular in order to trace the way that space-time is implicated in the biopolitical precarity that is embodied by the women with whom I worked across the eras of apartheid and post-apartheid South Africa.

6.3. Actors and Networks of Activism

This dynamic of othering the Eastern Cape surfaced in the course of my fieldwork when hanging out in Khayelitsha with the women I worked with and other activists who, in different ways, constructed Khayelitsha as a 'pioneer space'; a place that, in contrast to other parts of the country, had first provided ARVs to the public sector through the MSF trial, thus showing the government the efficacy of these medicines for sustaining life.

These activist narratives surfaced primarily when hanging out in these historic spaces of activism. They include the building where MSF and TAC had their offices in Khayelitsha and the parking lot outside the offices where we spent a good deal of time leaning against the wall or sitting on the pavement chatting. Historically, the space of Khayelitsha was an important political node in the anti-apartheid movement as people, like Yvonne's parents, worked with other activists in the ANC's underground movement to make these spaces 'ungovernable'. I suggest that Khayelitsha has not only been an important space of resistance against the apartheid and post-apartheid government, but women's lives in this site across these two political eras point to the continuities of embodied biopolitical precarity across these eras.

6.3.1. "They found out where we lived": Anti-Apartheid Activism and Biopolitical Precarity

The topology of Cape Town bears witness to the present history of apartheid as class and race are layered into each other and still largely and visibly spatialised, with Khayelitsha located on the furthest peripheral point (within the Cape Town metropole) from the business centre: predominantly white and wealthy people live and work in the centre that circumscribes Table Mountain, whereas Khayelitsha and the surrounding Cape Flats area is comprised almost entirely of Black people who move into the centre to find or undertake poorly paid work as unskilled labourers. Foucault's conception of governmentality, written at the height of apartheid, resonates with the force with which the apartheid government used a range of disciplining techniques (principally through legislation and powerful law enforcement infrastructure) to ensure the economic and political vitality of the state.

Looking back to the anti-apartheid struggle, Yvonne recollected moving between her parents' home in Site B and her aunt's home in Site C in order to be shielded from the police raids. This political violence, she explained, was directed at her parents and the activist cell they were a part of in Site B. The geographic proximity of Yvonne's parents to the other members of this cell was critical for maintaining secrecy; when the police intercepted this cell and arrested Yvonne's mother in 1990, the members of the cell became suspicious, thinking that Yvonne had disclosed information to the police when she was interrogated. As a result of this sense of betrayal within the group, Yvonne's family moved to Site C where they hoped to hide from the activists they had once worked with. In the quote below, Yvonne describes how this suspicion led to violence and, eventually, to the death of her step-father.

I think there was a leakage of information... So other comrades chased some families.

About 12 or 15 families were beaten in Site B. Those people they thought relayed the

information [of where we had moved]... I still remember when he was shot that day. They found out where we lived... We didn't know what happened. And then we heard that our father, our step-father, had been shot dead. He was killed... I think that's where our life changed a bit (Yvonne, 2011).

The conjunction of time and space in Yvonne's account points to a dynamic topology of activism against the apartheid state - a topology that engendered multiple forms of precarity for Yvonne and her family. Yvonne's family moved to live in Khayelitsha with the imperative of making this particular space ungovernable by the apartheid government – a government that, at its heart, stripped the humanity of South Africans in an extreme example of biopolitical precarity as “that politically induced condition of maximised vulnerability and exposure for populations exposed to arbitrary state violence” (Butler, 2009: ii). The space of Site B enabled coherence and secrecy among the network of activists that had coalesced in this space at this time; however, rumours sown by the apartheid police engendered distrust among members of this cell, resulting, finally, in the death of Yvonne's step-father, also a brutal example of biopolitical precarity and the stripping away of humanity, resonant with Agamban's (1998) *homo sacer* and the enduring tie linking the state of the body and the body of the state.

Yvonne's mother joined TAC before Yvonne became aware of her own HIV-positive status because she was dismayed at the failure of the government, a government she had risked her life for, to provide life-saving medicines to HIV-positive people. Like Zackie Achmat, the then-General Secretary of TAC, she was careful to distinguish between her political support for the ANC and her activism to challenge the government as a whole. Yvonne joined TAC in 2004, and unlike her mother, she associated the ANC with its leaders' – particularly President Mbeki and his Health Minister - obdurate refusal to provide ARVs. When challenged by Yvonne during their work together in TAC's Khayelitsha branch, her mother said, “I support TAC, but I will always be a card-carrying member of the ANC.” Yvonne's mother's response points to the complex struggle of former anti-apartheid activists in making sense of the government's betrayal of its citizens in post-apartheid South Africa.

Yvonne's family history reflects a broader historical trajectory, discussed in the next chapter, in which the particular space-time of activism in Khayelitsha generated new forms of citizenship under the post-apartheid government as activists traced the state of HIV-positive people's bodies to the government's failure to provide ARVs. For example, Lilian's illness and treatment narratives, describing how HIV and ARVs came to enter her body, are detailed in the previous two chapters and they, too, highlight a shift from the struggle for freedom under apartheid to

the struggle for life linked to essential AIDS medicines in post-apartheid South Africa. Lilian directly attributes the birth of her activism to the death of her child and her bewildering sense that the post-apartheid government was reneging on its constitutional obligations to citizens who had been stripped of their rights under the apartheid government. Lilian and I were talking about TAC's early activist tactics, including bringing generic medicines into the country illegally, when she told me about a friend who had also joined TAC because she was angry with the government's failure to provide treatment to prevent vertical transmission. She said, "And this is the government that we elected!" to underline her dismay at the democratic government's failure to provide life-saving treatment.

6.3.2. "[O]n the other side of the road, no ARVs": Post-Apartheid Activism and Biopolitical Precarity

The failure of the post-apartheid state to provide life-saving AIDS medicines presents a further and perplexing account of the topology of biopolitical precarity, as hundreds of people died each day of AIDS-related illnesses that could have been prevented had the government made ARVs available to its citizens. Khayelitsha is a poignant illustration of the extent to which biopolitical precarity persists across different government regimes, in very different contexts, at the time MSF started providing ARVs through its trial to many of the women and men with whom I worked. It was particularly striking, as Lilian's account below illustrates, because access to life-saving medicines was spatially circumscribed – available only to those people living in Khayelitsha.

The logic of public health care provision in post-apartheid South Africa relies on the principle of 'catchment areas' in which people in geographically demarcated areas are referred to corresponding community health centres. Lilian, Lihle and Nomfundo became close friends following their pregnancies with their first children in 2000. Lilian, at that time, lived in Langa, whereas Lihle and Nomfundo lived in Khayelitsha. MSF had started to provide HIV testing and treatment in Khayelitsha and Nomfundo, because of her location in Khayelitsha during her pregnancy, was able to test for HIV and receive treatment to prevent vertical transmission to her baby. Lilian was compelled to attend her local clinic in Langa for antenatal care; she was not tested for HIV, and even if she had been tested positive, she would not have been able to access biomedicine to prevent her child from contracting HIV, because the government refused to provide PMTCT through the public health system at that time. Although Lihle lived in Khayelitsha, she chose to go to a clinic in a different area. Lilian said,

I don't know what drove her to go for antenatal care somewhere else but not in her own area because she would have also gotten AZT if she had gone to MSF [in Khayelitsha]. But she didn't. And as a result both our children were born HIV-positive... [Nomfundo's] baby was born negative. It's the same year, but on the other side of the road, no ARVs. And on the other side there was MSF dishing out AZT and women were giving birth to HIV-saved children (Lilian, 2011).

Nomfundo and Lihle's children are twelve years old. However, although their children are both alive, Lihle's child is HIV-positive and struggles with the accumulative impact of a life characterised by persistent illness. These children have very different lives and possible futures; this is linked to the sites of their birth and the spatialisation of health care provision (or lack thereof) in Khayelitsha at the turn of the century. MSF provided ARVs in Khayelitsha whereas the state failed to provide ARVs through the public health centres that Lihle and Lilian accessed when they were pregnant. As a result, Lilian's daughter died a few months after she was born and Lihle's child is HIV-positive and currently on ARVs.

The stark implications of the government's failure to provide ARVs had direct biopolitical implications on the capacity of people just on 'the other side of the road' to live, and on the kinds of life – as Lilian reflects – that was possible for children who were born with HIV because their mothers were not able to access PMTCT. The biopolitical precarity of the government's failure to provide ARVs is still embodied as these children navigate life with HIV, in a socio-spatial topology that continues to reinforce socio-economic inequality.

Lilian linked the spatialisation of precarity to a broader issue around the injection of funding into Khayelitsha at the cost of funding development initiatives in the other areas of the Cape Flats:

We need to make the funders aware of that. Not everything should be about Khayelitsha and Soweto. Other areas should get the same services that we're given... [O]nly people from Khayelitsha benefited. Women from other places never benefited. ... If we put resources in one place then others on the other side of the road will feel cheated. This is the same for me. I feel cheated. There were no ARVs where I went (Lilian, 2011).

Lilian's assertion speaks to the complex interplay of government responsibility, on the one hand, to ensure the provision of services, with the role of non-governmental organisations like MSF, on the other hand, who move in to provide resources, like ARVs, when the government fails to do so. This account resonates with Prince's (2012) ethnography in Kisumu, Kenya,

where residents referred to their city as 'NGO city'; a cynical reflection on the global injection of vertical funding into local HIV programmes. Implicit in this reference to their 'NGO city' is a critique of programmes that do not consider the context in which 'life is lived' but focus instead on a narrow understanding of life linked to biomedical and other illness-related resources (Prince, 2012). Lilian, too, argued that there was a risk, with this rush of funding for HIV, that the state would transfer its responsibility for providing basic resources to its citizens on to NGOs and therefore distance itself from its constitutional obligations to citizens in remote or under-resourced areas.

6.3.3. Dynamic Topologies and Emergent Socialities

As the narratives above indicate, precarity cannot be mapped on to physical space but needs to be understood in relation to the political dynamics that are built into particular conjunctions of space and time. Although the contemporary place of Khayelitsha reflects the historical making of space through class and race relations under colonialism and apartheid, my fieldwork challenged prevalent conceptualisations of peripheral spaces, like the Cape Flats, as marginalised places. These conceptualisations reflect a discourse in which the history of multi-layered marginalisation creates conditions of alienation in everyday life (Lefebvre and Goonewardena, 2008) and is mapped on the surface of urban space (Keil, 2008). In my fieldwork, binaries like periphery/centre and impotence/power did not reflect the women's fluid recollections and their tactical negotiation and creation of a multiplicity of spaces, as illustrated by Yvonne's parents decision to move their children between Site B and Site C to ensure their safety, for example.

bell hooks argues that instead of mapping hegemony on to particular spaces, we should look at how spaces that are considered marginal, in this case the Cape Flats, can become a space of radical openness (2000). This is evinced in the clustering of anti-apartheid coalitions in places like Khayelitsha that were considered marginal; further, MSF's decision to provide ARVs in Khayelitsha made Khayelitsha a particular 'centre', a place that, as Zama and Sihle's story attests, many people travelled to from across South Africa in order to access life-saving medicine.

In considering the way in which space is woven into the politics of life, I suggest that marginal spaces are not areas that can be geographically demarcated, but rather, that they are illustrative of the state's complicity in the generation of marginalisation. In other words, these

cases illustrate the socio-spatial form of biopolitical precarity as it was embodied by men and women who challenged, first, the oppressive apartheid government and, later, the democratically elected government.²³ Further, the spatialisation of biopolitical precarity is embodied. As described above, embodied precarity was borne through women's experiences of violence during apartheid and by their experiences of loss and illness as a result of the post-apartheid government's failure to provide ARVs. These accounts across time indicate the way in which space can also operate as a locus for networks of resistance where people who experience marginalisation within and as a result of their bodies are able to negotiate and resist precarity. During my fieldwork, I came to experience Khayelitsha increasingly as the women did; not only as a space in which life was persistently precarious, as I discuss in the next chapter, but also as a space where the successes borne from a history of resistance against both sets of government continues to be felt. I return to Miriam's clinic, and the queue that marked the end of the monthly ritual to obtain these hard-won, life-saving medicines.

While waiting in the very long queue snaking out from the three pharmacy counters to the general waiting area of Miriam's clinic, we spent most of our time chatting to the large number of "comrades", as Miriam referred to them, who came up to greet her. When I commented on Miriam's active social life in the clinic, and particularly in the pharmacy queue, she smiled and said, "Sana, it's because we fought [for ARVs] together". The shared identification around a common illness, and the socio-spatial dynamics that I observed as people in the queue shared stories with each other that stretched back to the start of the MSF trial in 2001, suggests the spatialisation of biosociality and the relationship of time, an era of HIV activism, to biosociality in this particular clinic. In addition to the social relationships that had formed over time among HIV activists who had historically attended the clinic in order to receive ARVs through the MSF trial, the biosociality of this particular space in the clinic applied more generally to HIV-positive people on ARVs irrespective of whether or not they shared an activist history. While we were hanging out in the same queue waiting for her ARVs, Zama pointed out to me that, "It's no secret that we're all HIV-positive in this line. You see, that counter is just for us. If you want your ARVs, you have to be open now."

It appeared to me that the conversations in the queue took place between the 'comrades' – the generation of TAC activists that the women with whom I worked belonged to – and not

²³ The way in which these governments were called to account for their failure to protect the human rights of South African citizens is not the focus of this thesis and cannot be considered in detail here. I also recognise that the modalities of biopolitical precarity under each political dispensation differed radically, and this difference, too, is not the focus of this thesis and cannot be explored in detail here.

necessarily between most of the people who stood in front of or behind us while we waited. Instead, there seemed to be an implicit acknowledgement that although the queue to this particular counter indicated a shared illness, this need not translate into a social relationship. These dynamics may suggest more broadly that the historical context of activism played a role in compelling activists, like the women I worked with, to assert HIV as a central aspect of their identity and therefore to claim the clinic space in which their HIV was signified as one through which these historical relationships were reinforced. The following chapter explores the implications of these shifting socialities among this group of women, and also among a larger group of people who may or may not have been standing quietly in front of or behind us in queue. I reflect on the different ways that both groups – former ‘comrades’ who had fought together, and those who had not been activists in the struggle for ARVs – see and speak to the state in order to develop a fuller understanding of how people conceive the biopolitical relationship between their own vitality and that of the state.

6.4. Conclusion

In engaging with topology through the lens of social theory, particularly ANT, Mol and Law (1994) argue that the social does not exist in a single space, but rather: that it is performed in several kinds of space; and that there are networks in which distance is a function of the relations between actants. This chapter took their approach to space as fluid: like blood, it moves across the permeable boundaries of bodies and through political borders constructed to delineate catchment areas within a city, provinces within a country, boundaries across a continent. In this 'fluid space', neither boundaries nor relations mark the difference between one place and another: "Instead, sometimes boundaries come and go, allow leakage or disappear altogether, while relations transform themselves... Sometimes, then, social space behaves like a fluid" (Mol and Law, 1994: 643). The way in which the women I worked with accounted for HIV and ARVs entering and becoming animated in their bodies was a narrative (re)construction that, like blood and their networks, constantly shifted, thus rendering space and time fluid, remade through memory.

By exploring narrative in relation to Anamnesis, this chapter emphasises fluidity and partiality in the unending task of sense-making, specifically in relation to precarity, through the process of recollection and reconstruction. I recognise that this thesis is, in itself, a form of narrative construction. Perhaps, too, it is this dynamic of narrative that lies at the heart of Anamnesis as people dialogue with their own recollections of where they have come from to (re)construct

who and where they are. The narratives that are woven into Anamnesis, as explored in this chapter, are salient in both their form and their substance. In their form, the narratives extend from verbal recollection and reconstructions and include things that were unspoken. Stories of past and present are held in the photographs of Miriam's children in their school in Khayelitsha next to the photograph of Miriam at seventeen in front of her school in the Eastern Cape; in diary entries containing words and drawings of stories that were not, could not be, spoken about; in the partially built wood-and-sand home in the Eastern Cape that belongs to Zama's father, a legacy of a former life and potential for another way of living that Zama longs for when she is in Khayelitsha, and also derides when visiting this site 'back home'. In this chapter, therefore, narratives reflected a collection of stories that are simultaneously material and semiotic, that shift back and forth between past and present.

In their substance, the narratives were co-constructed with recollections of space and time, with embodied precarity linked, through narrative recollections, to these socio-spatial relationships. For example, as described in the earlier chapters, women's accounts of the pathways that brought HIV into their bodies implies an 'othering' of their childhood homes in the Eastern Cape as places that rendered their bodies precarious. However, when the women spoke of their anxiety about poverty in Khayelitsha, for example, the romance of the Eastern Cape's green valleys and safe villages become salient. As such, the narrative threads of Anamnesis are socio-spatial and partial depending on the kinds of memories that are invoked in different places and across different times. These situated knowledges articulate with space-time, suggesting that where people are located in these spatialities shapes how their partial perspectives and memories unfold. Therefore, this chapter suggests that Anamnesis, generated through narrative (re)construction, is spatialised; further, it demonstrates that situated knowledge, in contrast with Haraway's (1988) conceptualisation, is not static but constantly (re)negotiated through the dynamism of Anamnesis in which memories shift and change across space and time.

Thus, the threads of Anamnesis, of hope and memory, surfaced through the women's and men's accounts of where their life had started and where they hoped to die. However, beyond this facet, the most striking distillation is the thread connecting each of these topologies as the women and men I worked with strategically negotiated space and the capacities for life held within each of them. The will to live and the strategic production and engagement with space to negotiate life and mediate death, therefore, points to the implicit, albeit constrained, agency of women and men as they 'act on' and through networks to secure their vitality. In the

following chapter I explore, in essence, the two sets of people standing in the queue with Miriam; the one group of former AIDS activists who, often and openly, asserted their shared identity as activists and as HIV-positive people. The other group relates to the quieter group of people standing ahead and behind us in the queue. The latter group may have been quiet about HIV, but for the people I spent time with who had not been AIDS activists, there were many other concerns that they believed the government should address. I therefore turn to consider the diffracted biosocialities of these two groups, and the implications this has for citizenship and the evolving imaginaries of the state.

7. Sensate States

At the end of the previous chapter, we were standing in a queue with Miriam as her friends and mine stopped for a while to chat with us on their way through the large open hall; the hall was both an exit and entrance, with the pharmacy (generally the last point of the clinic journey) located in a corner of the hall next to the general waiting area (the first point for many in their health-seeking journey). The stream of people passing in and out of the clinic, and who joined us as we waited in the queue, created an ever-shifting node of playful, often proud, chatter amongst friends. This little node of friends cycled in size, growing and shrinking as we waited in an otherwise linear queue where solitude rather than sociality seemed to be the norm. The dynamics in the 'ARV queue' were differentiated among those more sociably engaged people – like the women I worked with - who had been 'comrades' in the struggle for ARVs, and those people who had not engaged in this struggle. I take this queue as an entry point for this chapter because it points to the way that space and sociality are produced over time, through memory, and because it indicates shifts in citizenship practices as they are embodied and as they coalesce around shifting biopolitical concerns. This chapter considers how these embodied 'new generation struggles' relate to emergent forms of 'everyday citizenship'. Therefore, this chapter also tessellates closely with Chapter Five and considers how the dual character of these embodied 'new generation struggles' have precipitated a corresponding set of citizen practices around, first, the intra-activity of HIV and ARVs, and second, the socio-economic spaces in which people's lives are lived.

Just as the memory of illness and the struggle for ARVs is held in the brown map on Zama's skin as a form of embodied Anamnesis, 'citizenship' was embodied in women's everyday lives as their experiences of shifting precarity flowed ceaselessly between past and present. Similarly, we see with Miriam's experience of side effects and her concern about developing resistance to second line medicines that her struggle for life did not end as the government started to provide ARVs. As such, this chapter explores how people make sense of their biopolitical relationship with the government in their everyday lives, with their narratives of precarity moving fluidly between past, present and future, between precarity and possibility. Although I reflect on medical anthropological conceptions of governmentality and citizenship, particularly therapeutic (Nguyen, 2005) and biological citizenship (Petryna, 2004), my fieldwork emphasised the importance of understanding 'everyday citizenship' as it is lived and embodied. Reflecting Cornwall, Robins and Von Lieres's (2011) call for a more nuanced

understanding of particular contexts, or states, of citizenship as they unfold across time and in very different spaces, this chapter engages with the visual methods of my fieldwork to explore people's imaginaries of the state as they 'saw' and 'spoke to' the state through the lens of their cameras.

Cornwall et al. (2011) articulate two pertinent imaginaries – how citizens see the state (Corbridge, 2005) and how states see citizens (Scott, 1999) – that generate the “mutually constitutive nature of the citizen-state relationship, and the extent to which different kinds of states make different kinds of citizenship possible” (2011: 8). There is, as these authors argue, very little research on governance and citizenship that explores the extent to which these imaginaries shape what it means to be a citizen. With this in mind, the political dimension of my research sought to trace these imaginaries through my fieldwork, and particularly through visual anthropological methods like photography and film. Here, too, it was apparent that women's political engagement with the state through their citizen practices was fundamentally connected to the embodied ramifications of AIDS medicines in their lives. Moreover, I found that, with the provision of ARVs, the landscape of citizen action had fanned out from a set of therapeutic claims that linked access to medicine with the right to life to include conditions that made life possible in contexts of intransigent socio-economic inequalities.

These emergent citizenships relate to the new generation struggles that were salient in my fieldwork. Chapter Five considers the dual character of these struggles as they flowed between the 'inside' and 'outside' of the body; looking into the body, we saw how women embodied precarity linked to the dynamic intra-activity of HIV and ARVs as they were felt in side-effects, treatment fatigue and viral resistance. The first section of this chapter outlines the emergent political concerns that relate to these embodied accounts of precarity with(in) the body. The second characteristic of the new generation struggles centred on the socio-economic context in which women navigated their everyday lives. The second section of this chapter, therefore, considers the political dimension of these embodied concerns with respect to 'life as it is lived' beyond the historic activist construction of ARVs as 'technologies of life'. This section traces these emergent struggles around the contingencies of life, now with ARVs, that remains biopolitically linked to the state's responsibility to ensure a broader set of rights around gender, sexuality, education, housing and sanitation. It suggests that historic socialities built around HIV as a shared predicament have diffracted from this singular focus to include these plural struggles that, too, are embodied as biopolitical precarity.

This chapter explores how ‘everyday citizenships’ were articulated through multiple forms of citizen action across the continuum between private and public spaces, and as they surfaced in people’s visual and narrative accounts of where they saw and spoke to the state. Together, these imaginaries point to the intimate and intricate relationship between the state and people’s everyday lives. I therefore show how the two facets of my research focus come together in this chapter and the next. Over the two sections of this chapter in particular, I suggest that: it is through the body that people experience the extent to which they are networked into a biopolitical assemblage; and that, because biopolitical precarity is embodied, it is also through the body that people experience and practise dynamic forms of citizenship in relation to similarly dynamic forms of governance.

7.1. Sustaining Life on ARVs: Between Rights and Responsibility

The majority of the people I hung out with during my fieldwork had joined TAC between 1999 and 2001. This period in South Africa’s history, as Steven Robins has observed through his research with activists in Khayelitsha, was marked by a cadre of therapeutic citizens who testified to the transformative effects of ARVs in their lives; at this time, many of the public ‘testifying’ activists, like Nondumiso, received ARVs through the MSF trial. Robins describes how biosociality was forged with this particular group of activists through a set of practices, like wearing the iconic HIV-positive t-shirt, attending marches and testifying to power of ARVs; these practices cohered around a set of discourses that asserted the positive effects of ARVs as life-giving in order to compel the government to provide these medicines through the public health sector (Robins, 2006). In making a set of biopolitical claims on the state at this time in South Africa’s history, before ARVs were publicly available, AIDS activists asserted an almost ‘democratic body’ in which all HIV-positive people’s bodies were cast as equally vulnerable to the effects of the virus, and therefore equally in need of ARVs.

Biosociality persisted in my fieldsite, but in a less cohesive structure to the early form it took among AIDS activists, a group described by Rose and Novas (2005: 449) as the “main example of biosociality”. Returning to Rabinow’s (1996) assertion that the social cannot be separated from the biological, if we think about HIV and ARVs as actants, as ‘things’ with a social life, and as things that move into the permeable body through social, economic and political relationships, then perhaps it is possible to start thinking about intersections of biosociality: as the effects of these actants are individually embodied; but socially visible and collectively

presented as 'new generation struggles' - which are, in turn, articulated through forms of 'everyday citizenship' as people saw and spoke to the state.

7.1.1. "I voted for my treatment": Embodied Rights and Biopolitical Citizenship

In May, a week after the Municipal Elections, Thandeka and I were walking down Queen Victoria street in central Cape Town; not only did the name of the street speak to the colonial legacy of South Africa, but the Memorialised 'Slegs Blankes/Whites Only' bench that we passed outside the High Court was a reminder of South Africa's more recent history. At this point in the road, Thandeka stopped me and pointed – not at the bench – but across the road to the Parliament Buildings. Thandeka was speaking about a much more recent history – one that she had actively shaped through her affidavit and testimony in the court case that TAC brought against the government to compel them to provide PMTCT. When we met earlier that day, the first thing she did was to show me the indelible black stain on her thumbnail – a sign that she had voted. I asked her why she had chosen to vote. She replied, "I voted for my treatment."

We were on our way to TAC's national office, just two blocks down the road from Parliament, walking slowly and talking even more slowly. Our conversation moved across time as our bodies, too, moved through spaces that had been politically potent in apartheid South Africa's struggle for democracy, and later, in post-apartheid South Africa's struggle for ARVs. Moving back in time as we moved through these city spaces, I asked Thandeka about her recollections of the 2004 National Elections. At that time she had been working with TAC for a number of years and had been particularly instrumental in TAC's early struggle against the pharmaceutical companies in 2001, and then against the South African government to access PMTCT. Her response was striking for me because, for the time ARVs were not available in the public sector, it appeared that Thandeka had attributed this to specific members of the ANC, whereas she believed that the government as a whole would eventually come to fulfil its obligations to HIV-positive citizens. Speaking about this period in South Africa's history, she said, "I put my eggs next to government. To give the people the treatment because the people, they infect the children. So they must access the AZT and nevirapine".

Thandeka pointed at Parliament, its white buildings barely visible over the green trees of the bordering Company Gardens that ran along Queen Victoria Street, and said, "I was here in parliament; I was talking about the treatment". We walked in silence past the bench; our

conversations had more silences than words. When Thandeka spoke, it was very softly and I needed to lean in to really hear her. Thandeka's voice has been particularly powerful for TAC's activism; her activism, like Lilian's, was born from her anger with the government for failing to provide PMTCT to stop HIV from travelling along vertical pathways into her daughter's body. She explained her work in TAC to me as we walked:

I was pressuring the government, saying, 'You must give us the treatment because the people are dying'. The government – [former Health Minister] Manto Tshabalala-Msimang – was not giving us the treatment. They were telling us that if we had HIV, we must take the veg. They didn't tell us about the treatment; they didn't want to tell us what was the right thing to us. They ignored the virus (Thandeka, 2011).

"When did they start taking things seriously?" I asked. "As I give them pressure!" she replied as we turned right onto Wale Street and walked to the bottom of the stairs of the St George's Anglican Cathedral. The Cathedral is situated next to the Parliament Buildings, in the Company Gardens, and has been used historically by apartheid and post-apartheid activists alike as a site of resistance and a place of mourning. It was, in fact, the same place where TAC had first assembled, almost thirteen years previously. The Gardens, which move out from the Cathedral, mark an important politico-judicial intersection with the High Court on the right and Parliament on the left. It was through these two spaces of the state spanning policy development and juridical implementation, that Thandeka worked with TAC to challenge the pharmaceutical companies, and later the government, to provide AIDS medicines to stop HIV from travelling along vertical and horizontal pathways into people's bodies.

Looking up at the Cathedral's towering façade, Thandeka said, "I know this church. I was here for the funeral service for Nkosi Johnson. My daughter came to light the lamp in the service." We were silent for a time before she said, "You know Nkosi [Johnson] died of HIV?" Nkosi Johnson, like her daughter, contracted HIV at birth; he was twelve years old when he died on 1 June 2001, slightly younger than her daughter in 2011. At the time of his funeral, Thandeka's daughter was three years old, and extremely frail. Both Thandeka and her daughter had just started ARVs through the MSF trial in 2001; as we see in the final section of the previous chapter, HIV-positive people who lived outside Khayelitsha's catchment area, on the 'other side of the road' to the MSF trial, were likely to die without access to AIDS therapies. The fragility of life and the possibility of death was, in biopolitical terms, underpinned by the rapid rate at which Thandeka's colleagues in TAC were dying because they could not afford to pay for private health care. We stood outside the cathedral, our necks straining. I commented that Nkosi Johnson had, like Thandeka, also spoken to former President Mbeki. "TAC's a very good

organisation. They opened my eyes to see what is the wrong way, and what is the right way. Because HIV is killing everyone. It's not just killing the Black people. So Mbeki was wrong." This quote highlights TAC's pivotal role in reshaping government policy in order to really 'democratise' health because, as Thandeka notes, the virus did not discriminate; this comment also speaks to Mbeki's assertion that HIV was being discursively mobilised by racists to perpetuate the myth that Black people are more likely to be sexually active and therefore more likely to be HIV-positive (see Van der Vliet, 2004; Fassin, 2007; Gevisser, 2008).

Like Thandeka, Yvonne worked with TAC in the early 2000s to compel the government to provide ARVs. She spoke with vehemence, saying, "I was angry then as I am still angry now. I was angry at that time because I knew that the government we were trying to approach is the government we voted for. And they kept denying our needs as a citizen in society." In 2011, Yvonne took many photographs in which she spoke to the state and directed her criticisms towards poor housing and education and the escalation of rape. Yvonne also took photographs of her medicines, but in this case, her photographs spoke to the work that she had done as a TAC activist to challenge the government, as health citizens, to provide AIDS therapies through the public health system. She had voted in the municipal election, but as she said, "I vote to vote." She had, however, opted to abstain from voting in the 2004 National election because,

I hated the government at that time, even during the voting times, I preferred not to vote, I thought what is the use of voting? I thought that soon I'd die and what's the use of voting for people who don't care about me. In order to vote I need to vote for someone who is taking care of me, of my needs, ARVs is the first need I knew I needed... They kept playing with words, saying that HIV doesn't cause AIDS, although you knew that if you're living with HIV you know at some point you'd have AIDS. They were politicising everything, they were playing with our minds... ANC members would follow whatever statement Manto [Tshabalala-Msimang] or [former President] Mbeki said because they are our leaders... We need healthy food and healthy diet, but we need ARVs. They must work together (Yvonne, 2011).

Although Yvonne expressed discontent with the conditions of life, particularly linked to service delivery and safety, she acknowledged that, in 2011, the government had made significant advances towards fulfilling its obligations to HIV-positive citizens by providing AIDS therapies.

Now, I don't lie. They are trying a lot: from the changing the ARV protocols, to convincing people to test, doing more campaigns on HIV, and also taking a lead. On 1 December 2009, the Minister of health and President took the lead and did VCT

[Voluntary Counselling and Testing]. That's what people need, to see their leaders take a stand on HIV (Yvonne, 2011).

With the changes in health care provision that Yvonne describes above, I wondered if Thandeka, too, felt that the government had started to 'care' about citizens' health now. Her decision to 'put her eggs next to the government' seemed prescient: she explained to me that, it's better now, because if you go to the clinic, to get treatment, you see the changes... Like the d4T; they don't use it in the clinic here in Khayelitsha because it makes a problem for the people - they are losing the shape through it, through d4T. They're monitoring the people, who're taking the treatment all the time. Now it's easy to go to ARVs; we see that people are healthy on the treatment (Thandeka, 2011).

As I came to know Thandeka and learnt more about her history as an anti-apartheid activist and then later as an AIDS activist, I realised that it was important for her – and many others, including Yvonne's mother, for example – to distinguish between challenging the government (as she had during the struggle for democracy) and challenging the government's AIDS treatment policy (as she had during the struggle for ARVs). TAC's founder, Zackie Achmat, also asserted this distinction, saying that he did not question the government's leadership, but rather the leadership of then President Mbeki and Health Minister Tshabalala-Msimang who were advocating pseudo-scientific approaches that questioned the link between HIV and AIDS, and challenged the efficacy of ARVs (Geffen, 2010).

Thandeka and I spent about six months searching for a photograph that had been taken of her and her daughter. Our search took us through the Company Gardens, past parliament, and down into the bowels of the adjacent South African National Gallery. The outcome of this search was unanticipated and I describe it here because it encapsulates the journey that, in part, brought activists like Thandeka and Yvonne to believe that the government has come closer to fulfilling its constitutional obligation to ensure citizens' rights to life and health by providing AIDS therapies in the public sector.

We did not find Thandeka's photograph among the hundreds of images we went through in the National Museum; nor did we have any record of the name of the photographer in order to track the photograph down in this way. It happened that one day, in July, I asked to use the adjacent office to the one I worked in at TAC's national office in order to conduct an interview. I walked in and saw Thandeka and her daughter's face looking out defiantly from the photograph on the wall. Inside the frame and next to the photograph was Thandeka's affidavit in which she called on 39 pharmaceutical companies to drop their case against South Africa

(because the government had used the 1997 Medicines Act to accord power to the Health Minister to override Patent Laws in health emergencies). TAC worked with the government to win the case (the 39 Pharmaceutical companies backed out) and, as described in Chapter Four, went on to sue the government in 2001 for going back on its agreement to provide nevirapine to prevent vertical transmission. Thandeka gave an affidavit in support of TAC's claim against the pharmaceutical companies in 2000; she also testified in the subsequent trial against the Health Minister in 2001. The salient points in Thandeka's affidavit, which ran alongside a photograph of her and her daughter in their home in Khayelitsha, said:

1. I am a 30 year old woman living at 41138 Makhaza, Khayelitsha. I am not married and have two children, the elder one is 16 years old and the other one is three years old.

5. In 1998 I became pregnant but unfortunately when I was three months pregnant the father of my child died from an accident. My baby was born HIV positive, it was very bad because at that time there was no mother to child transmission (MTCT) prevention programme.

8. It is very painful for me to see my child suffering from the same illness like mine and I think that if the MTCT prevention programme had been implemented, my baby wouldn't be HIV positive.

9. I would be very happy if we (me and my baby) could have access to treatment to help us live longer and healthier lives.

10. It pains me to see people suffering and some die because they can't afford treatments because of their prices. I would be very happy if pharmaceutical companies could give us the treatment at cheaper prices. Most people who are living with AIDS are unemployed and we can't even buy something to eat, so how can we pay for expensive treatments.

SIGNED ON THIS DAY OF FEBRUARY 2001 AT

Figure 7.1. Affidavit in TAC's Court Case against the PMA (Source: Thandeka, 2001)

In July 2011, at the end of my fieldwork and after the six-month search for this photograph, Thandeka and I returned to TAC's national office, climbing the stairs that spiralled up past Sonke Gender Justice's expanding offices. After first looking at it and telling my colleagues working in TAC about the journey she had taken as an activist with TAC many years previously, we went upstairs to say hello to the people Thandeka knew in TAC's administration. After

chatting to her former colleagues and friends, we had gone back to look at the photograph one more time. I had thought that perhaps Thandeka would mind that her photograph was in this office and not in her home or that, at the minimum, she would mind that it was being sold for a large amount of money online by the photographer and that she had not received any payment herself. However, when I asked her, she smiled and said, “Look at me now Beth! If you saw that woman and child from the photograph then, all those years back, you would not believe they would still be alive today. But here I am. I am fit; I am me.” The only other times I had seen Thandeka smile like that was when she was with her daughter. I realised that my concerns were not hers, and that finding the photograph was not a journey to reclaim the image, but one to acknowledge the distance she and her daughter had travelled over the past decade as they navigated their will to live.

The changes in the governance of HIV over time in South Africa indicate the power of large-scale forms of activism led by organisations like TAC and the former AIDS Law Project; but they also came down to the individual acts of people like the women I worked with as they argued for their rights, as citizens, with a government that they voted for. A government that, as Thandeka said, people ‘Put their eggs next to’ in the hope that they would, eventually, fulfil some – if not all – of their responsibilities. In this sense, Fassin’s comment on the continuities across apartheid and democracy is pertinent. He writes, “Despite facile academic use of the prefix post-, this can indeed be called the postapartheid period. No other term expresses so well the dialectic of a social world that has survived its own disappearance” (2007: xvi). Anti-apartheid activists had fought to give life to a democratic government, led by the ANC, with the belief that their own vitality would become less precarious than it had been under apartheid. However, as we see here, and with Yvonne’s mother’s perplexed relationship with the government she too had fought for, the possibility of life for HIV-positive people was powerfully constrained by the post-apartheid state’s refusal to provide medicines.

Until it finally did. Then, as my ethnography shows, a new range of biopolitical struggles became prominent in people’s bodies and in their social, political and economic relationships; in particular, the coherent set of biosocial discourses that positioned ARVs as a ‘solution’ to the shared predicament of HIV started to diffract. The provision of ARVs, and their role in sustaining people’s lives, was perceived as absolutely critical, but this appeared to be enmeshed with more complex sets of narratives including: an emergent ambivalence towards ARVs linked to the side-effects, viral resistance and adherence; and an expansion of the biopolitical relationship with the state – formerly tightly articulated around ARVs – as HIV-

positive citizens called for the provision of a broader set of resources that were necessary to support life in addition to ARVs. In the following sections I look at how responsibilities for 'life' draw in adjurations by activists to be 'disciplined' and care for the self, in Foucault's (1998) terms; and I also show how these imaginaries of the state connect to diffracted biosocialities as people articulated, through everyday citizenships, their perception of the state's responsibility to sustain their vitality beyond the provision of ARVs.

7.1.2. "[The government] is ... managing our health": Rights and Responsibilities in the Era of ARVs

Me: Why do you think it's the government's responsibility to provide ARVs?

Zama: Because he's the one who's got money, mos.

Me: But why does that mean it's the government's responsibility?

Zama: Well, whose responsibility should it be?

Me: Well, to play the devil's advocate: why should we not pay for the ARVs ourselves?

Zama: Because we don't have money. Other people are not working. Some people are working, but their salaries are very low and the medicines are expensive.

Me: I know I'm starting to drive you crazy. But...

Zama: But...

Me: Ok, so what if the American government offers to provide all the ARVs in South Africa; should our government still pay for the ARVs?

Zama: Ya, to show responsibility, mos. Because we see the government as the person who is managing our country. He is part of managing our health, employment, other areas, poverty. Most of the areas in our life. I think that is why we feel the government should be taking the responsibility

Me: Because it's managing all these areas, it should be managing our bodies?

Zama: Well, not managing our bodies in that way... Hm... Well, sometimes it's ok.

Me: Do you feel it's ok for the government to manage your body?

Zama: In some contexts, yes. Sometimes people, they don't listen. You tell them this, then they do things the other way. They know that HIV can kill you; that condoms must be used. We know that ARVs can save you. We know that we must be honest with our partner. We know we must go for a test earlier to prevent illness and other infections. But people don't do that. It's scary... So now. We must test those people. By force. Nicely [laughing]. So that they know, man.

Although Petryna (1998) and Nguyen (2004; 2006) explore systems of claims that arise from biopolitical techniques that govern populations, they foreground distinct subjectivities that collectives lay claim to through citizen practices. The emergence of new generation struggles, after the public provision of ARVs, points to the importance of understanding the dynamic ways in which ARVs and HIV, as actants, intra-act with(in) people's bodies. This confounds prevalent conceptions of citizenship linked to health or illness, like biological and therapeutic citizenship: although people still conceptualise their relationship with the state in biopolitical terms, as Zama does here – '[the government] is part of managing our health' – their embodied experience of precarity is subjective and shifting, held in individual bodies and not necessarily shared by a collective citizenry. I introduce these diffracted biosocialities in relation to the 'new generation struggles' in Chapter Five. In this section, I explore how, despite these shifting subjectivities, there was a consistent view among the people I worked with that the state was still implicated in their embodied precarity, and that it continued to be responsible for ensuring a set of rights linked to a broader set of concerns beyond access to ARVs.

The people who coalesced around Miriam in the 'ARV queue' had been part of the biosociality that emerges from shared activist practices, and in my fieldwork there were two overarching approaches to managing these struggles. On the one hand, as discussed in Chapter Five, the people I worked with asserted the importance of self-care practices or, as Robins (2006) describes, responsibilised health citizenship where the responsibility for providing AIDS therapies lies with the state, but the responsibility for adhering to the medicines and 'living positively' lies with the individual. On the other hand, the people I worked with said that although self-care practices were important, it was also the government's responsibility to ensure that people were supported to manage the 'new generation struggles' linked to side effects, viral resistance and adherence.

Some of the activists I came to know berated people for failing to adhere because they were 'not managing their health' and argued that an individual's failure to adhere to treatment warranted 'punishment'. This took many forms; in some cases it was simply a matter of asserting the right of doctors and nurses to scold HIV-positive people for failing to strictly adhere to their treatment regimens. In other cases, as with Thandiswa's sister, it entailed a refusal on the part of her sister's doctor to move her sister onto lamzid - a better but more expensive ARV with fewer side effects.

Thandiswa: My sister, this one, she likes freaky! She drinks and likes parties; they're careless... She's on ARVs. But they didn't take ARVs now... because they like to spend the nice time with the drinking and the dancing.

Me: So she forgets to take her ARVs?

Thandiswa: You see! ... This treatment, lamzid, they give if people have a serious problem. But they want to know if you are responsible to take it all the time. If you don't, like my sister as they do now, they didn't give to her because they tell us this treatment is very very expensive."

Thandiswa's account speaks to a broader field of ethnographic research in which relationships in health centres are viewed through the lens of governmentality and biopower (Prince, 2012; Le Marcis, 2012). For example, through her ethnography of life in Kisumu, Prince (2012) critiques a straightforward application of the 'politics of life' framework on large-scale antiretroviral (ART) interventions:

ART programs have a circumscribed objective: to ensure what Arendt (1958) calls 'sheer survival' ... through providing the basic necessity — medication. At the same time, they present successful survival on ART as a matter of 'positive living', of orienting one's life to the goal of health. ART programs both encourage people to think of themselves in terms of their biology, and triage survival, as they produce new forms of inclusion and exclusion (2012: 537).

Thandiswa's account indicates an interpolation of the 'right kind' of patient that ARV programmes produce through the discourse of positive living, in which 'liking freaky', drinking and staying up, are not considered 'responsible' behaviour. However, her account also takes the 'politics of life' critique further as it points to economic rationalities (and fears) of the state's limited capacity to provide ARVs; and it links these deep concerns about sustaining life on ARVs in the future with discourses that are, perhaps, less about moral forms of exclusion and more about wishing that her sister would lift some of the weight of responsibility in the strained household they shared.

While Thandiswa concurred with the way her sister, Yoliswa, was punished by the nurses in the clinic for failing to adhere to treatment, she also asserted an economic rationality for this punishment: 'this treatment is very very expensive'. In his study of the Brazilian response to AIDS, Biehl (2005) describes a set of economic value systems that draw pharmaceutical commerce into public health care; Thandiswa, here, points out this value system, where 'discipline' should correct aberrant behaviour that undermines adherence to expensive medicines and therefore 'costs' the government money. An unspoken concern, perhaps, was

that if the government was ‘wasting money’ by treating people who did not adhere to their drugs, then it would also be less able to afford to provide newer medicines, like lamzid and third line treatment like raltegravir, to those who did. This, too, fuelled the logic of governmentality in which biopower, operationalized by health practitioners through adherence checks for example, conditions people’s bodies by ‘rewarding’ those who conform to disciplinary practices.

Another aspect of Thandiswa’s account here, and of the relationship I observed with her sister over the course of my fieldwork, was an abiding frustration that her sister’s social behaviour placed an additional responsibility on Thandiswa to care for her sister’s children. Yoliswa lived with her two children in a small shack in the back garden of Thandiswa’s RDP home. One child, the same age as Thandiswa’s daughter, was also born with HIV, and had become severely disabled in the ‘window period’ in the late 1990s before the government provided PMTCT or any AIDS medicines for babies with HIV. Often, when extremely drunk, Yoliswa did not come home in the evening and implicitly relied on Thandiswa to feed and bath her children and help them finish their homework. This, on top of struggling with her own son’s drug addiction and daughter’s precarious health, was extremely taxing for Thandiswa. If Yoliswa was ‘successfully’ disciplined by the state to amend her behaviour in order to qualify for better medicines, then it was conceivable that these changed behaviours (like abstaining from alcohol) would relieve some of the burden of responsibility that Thandiswa felt in caring for Yoliswa’s children. There is a further dimension, then, to Yoliswa’s economic rationalisation underpinning ‘good adherence behaviour’. Robins (2005, 2010) describes this process as one in which people, particularly activists like Thandiswa who were linked to TAC and MSF, become ‘responsibilised citizens’.

In the course of his fieldwork with HIV-positive activists in Khayelitsha, Robins observed how people’s illness narratives and treatment testimonies produced “radical transformations in subjectivity and identity that go well beyond conventional liberal democratic conceptions of ‘rights’ and ‘citizenship’” (2010: 128). I also observed this among the group of people I worked with who had not necessarily been activists, but who were also on ARVs; almost everyone said that they had changed their lives radically after learning they were HIV-positive. These changes included abstinence from alcohol, increased condom use and a reduction in the number of concurrent partners with whom they were having sex. It seems, though, that when people like Yoliswa do not adhere to the set of behaviours expected from ‘responsibilised citizens’, that they are not only punished by the health system, but also by their peers. Here, too, this may

relate to the economic rationalisation that I discuss above: ‘good people’s’ ability to access drugs is conditional on the government’s ability to pay for them (which, as I discuss in the next chapter, links them into a global assemblage). This, in turn, is conditional on people agreeing to be responsible not only to their own lives, but to the lives of others by adhering to these life-giving and costly medicines.

Citizens like Thandiswa, and those with whom Robins (2008) worked, therefore actively enter a biopolitical relationship with the state in which they agree to ‘behave’ in particular ways in order to access the biomedicines on which their vitality hinges. This dialectic of punishment and reward has direct and embodied implications. As I discuss in Chapter Five, many of the women I worked with struggled with issues around adherence; but they were reluctant to discuss these struggles because of the stigma attached to being an ‘irresponsible citizen’.

By placing the responsibility on individuals to ‘behave’ and punishing them if they do not, I suggest that this form of governmentality creates a value system linked to what Biehl (2008: 100) describes as the “pharmaceuticalization of governance and citizenship”, which can then crystallise new inequalities. In this respect, these inequalities are embodied as people are ‘permitted’ to access newer and better medicines if they ‘behave’, and they emerge in social relationships as those people who struggle to adhere, for a complex range of reasons, are deemed ‘irresponsible’ and less ‘deserving’ of expensive medicines.

In my ethnography this form of governmentality, held in a contract of vitality where ARVs are ‘given’ to ‘responsible’ individuals, was mobilised around multiple notions of responsibility: as individuals are told to be ‘responsible for their own health’; and as the government was described as ‘responsible for managing our health’ by providing ARVs to its citizens. As ARVs were made increasingly available in South Africa, and as people were on the medicines for a substantial period of time (a decade, for many of the women I worked with), this contract of vitality drew a broader set of concerns around medicines into focus. In a conversation with Miriam and Yandisa, they told me that not only should the government be working harder to bring third line ARVs into South Africa, but that it should be working to eradicate HIV from their bodies altogether. In talking about why she believed the government was responsible for these newer biomedical technologies, Miriam echoed the economic argument that both Zama and Thandiswa had explained to me:

The Private companies are doing this for profit - they can’t give us the medicines for free, so the government is responsible. They make promises to do everything for us.

Firstly, they must supply work. It's difficult to be employed these days. Medicines are expensive and we don't have money. The only thing we want is health. We've got children to live for. And there are these children who are HIV positive now, they didn't go out and find HIV, we infected them with HIV. At least he must find a cure so that our children must be healthy and live their own lives (Miriam, 2011).

For many women in the core group, their sense of precarity was not linked to whether or not they could access medicines at all, but whether or not they could access third line treatment in the future when ARVs were no longer successfully intra-acting with HIV to stop it from replicating.

While Yvonne noted a number of changes that had occurred in the health system as a result of TAC's activism and the change in the leadership of the ANC-led government following the national elections in 2009, she asserted that the struggle for life linked to AIDS therapies was far from over.

I can vote a 100 times, there will be no changes... I have ARVs, but what if I failed from this line one and go to line two. What will happen to me then? There are no other options... They [the government] always complain about money, and for me, I think we do have money but the money that we have is the money that they use for their own benefits. South Africa has lots of money: look at [President] Zuma! He has so many wives, children, a beautiful house, cars, he always uses the private jet. That's South African money... but they use it for them, not for us (Yvonne, 2011).

Here, Yvonne's concern about accessing new generation medicines speaks to a broader concern around corruption, where money that should be used 'for us', for citizens, was instead being siphoned off to pay for President Zuma's private jet, his cars and his family.

The possibility of developing resistance was not only an abstract concern but a 'new generation struggle' that she had already experienced. As discussed in Chapter Five, in 2009 she found that AZT had made her anaemic and that nevirapine was damaging her liver. Yvonne was then put onto a different treatment, but struggled with lipodystrophy – a side effect of d4T. Yvonne echoed Zama and Thandiswa in saying that the government needs to work harder to support people with these 'new generation struggles'. One such route, she suggested, was by reinstating support groups for people not only as they start their ARVs, but as they manage the longer-term struggles that surface in people's bodies and lives over time.

Sibongile, Zama, Yvonne, Miriam, Lilian and Brenda had all been members of support groups when they started their ARVs. This may perhaps account for their concern that, with fewer support groups available to those living with HIV, people were less likely to discuss concerns around side effects with member of their group and then with medical staff, and therefore more likely to default from their treatment.

Sometimes people get bored because it's a life-long treatment because people say, 'All these years I've been on treatment, and now I'm tired'. Also side effects, as I've experienced with side effects on d4T. I tell myself that if the doctor does not want to change me, I'll stop taking ARVs... [Now] I think their main focus now should be, yes, ARVs are here and how do we keep people on them (Yvonne, 2011).

The historic recognition that ARVs are an essential part of managing HIV was not questioned in my fieldwork; but an emerging and embodied ambivalence about these medicines became salient, diffracting the coherence of earlier forms of biosociality based on the construction of ARVs as the solution to HIV, with implications for the broader set of claims made by HIV-positive citizens on the state. Yvonne points to the importance of taking time into account when thinking about ARVs. In this and the previous chapters, we see how ARVs came to be embodied in ambiguous ways over time: in addition to playing an important role in sustaining life, ARVs were also embodied as side effects. D4T, for example, surfaced visibly in the body as lipodystrophy, and as we see in the next chapter, some of the effects of ARVs do not simply recede into the body with time when people move onto different drugs. Similarly, the effects of HIV too, can remain visible as we see in the embodied memory of the virus held in Zama's skin. Further, embodied precarity is not only related to the lives of HIV and ARVs individually, as actants in the body, but also to their intra-action with each other; this is evident, for example, in viral resistance as new strains of the virus become better able to combat the effects of older AIDS medicines.

These new generation struggles are linked: daily adherence to medicines that sustained life but also generated side effects became a fraught personal battle for the women I worked with. With erratic adherence (to minimise side effects), and also with unprotected sex with another HIV-positive person, the virus becomes adept at mutating, and therefore resisting ARVs, weakening the body and making it more susceptible to opportunistic infections. In Chapter Four, Miriam and Brenda's accounts of having unprotected sex with their partners suggest the social and economic dimensions entailed in their 'self-care'; they may be 'living positively' in respect to their adherence, but their ability to practise safe sex is relational. It is also reflective

of entrenched socio-economic inequalities where, for instance, Miriam's education was halted by her uncle so that she could be 'a good girl' and care for her dying mother. Lilian and Yvonne's experiences of lipodystrophy and liver dysfunction, also discussed in Chapter Five, point to the social dimensions of their encounters with biomedical health practitioners who did not, initially, take their concerns about side effects seriously.

Therefore, although the virus mutates inside the individual body, it is able to do so because of the intersecting pathways of precarity that foregrounds sociality. This includes horizontal pathways and women's constrained ability to negotiate the frequency of sex, and the use of condoms, with their partners. Further, although women experience the side effects of older and less effective ARVs in their body, their struggles around adherence and viral resistance points to a broader set of social relationships with their medical doctors and political relationships with the state and its capacity (or will) to provide more effective AIDS medicines to minimise these effects.

Diffractional biosocialities emerged as women started to articulate their embodied struggles with what had historically be cast as the solution to managing HIV. The articulations of their struggle – not only with HIV as the quintessential 'biology' but now also with ARVs – traversed roads that had been well worn in the earlier struggle for ARVs, including: their relationships with biomedical health care practitioners, an array of national and transnational activist organisations, and local, provincial and national government officials. As I go on to discuss, these social, political and economic relationships are not distinct but networked into each other; they are also indicative of diffractional biosocialities as women negotiate their relationship with the actants they embody, and with the broader intersecting inequalities and opportunities that they navigate in their daily lives and within a network of actors that co-construct their embodied precarity and their vitality.

The injunctions entailed in 'positive living' have been strongly critiqued by other anthropologists in their ethnographies of ARV programmes for placing responsibility on the individual while failing to account for the complex realities of their lives; realities that, as shown in Prince's (2012) ethnographic research in Kisumu for example, may mean that ARVs make it even more difficult to live because living entails having enough money to buy food in order to manage taking ARVs: a negative cycle ensues as ARVs themselves can exacerbate hunger pangs, and because they can make people quite dizzy, it becomes even more difficult for them to work the long hours necessary to earn the money they need to buy food for

themselves and their household. Being HIV-positive has been historically considered in light of its biosocial potential to connect people to resources – as problematised in Chapter Five with respect to *uYaphi*'s income generation programme. However, when these resources dwindle, the biopolitics of life beyond biomedicine become more keenly apparent, as I observed in the range of claims that people made when 'seeing' and 'speaking to' the state.

7.2. Sustaining Life beyond ARVs: Seeing and Speaking to the State

In addition to calling on the government to respond to new generation struggles linked to the intra-action of HIV and ARVs, this group of women spoke about the linked struggles they encountered as they navigated the longer life that was, in part, made possible through ARVs. This second strand of emergent citizenship forms the focus of this section as people articulated spaces in which they saw the state, and practices through which they spoke to the state in order to make it listen to their concerns.

Over the course of my fieldwork, the ten women in the core group and I would reflect on our relationship with the state in the different spaces of our lives. We started quite generally, by playing with photographs and films, capturing the most important moments and people that had surfaced in the time between seeing each other. Over time our conversations moved into reflecting on where we had felt disappointed by the government: in my frustration at South Africa's performance at the UN and its vote on the removal of sexual orientation from extrajudicial killings (in a photograph of the march outside parliament); or in Miriam's anger at the police who had arrested her brother for selling alcohol illegally (in a photograph of the locked up *shebeen*). These visual accounts became a layered conversation that looped across time. For example, I took a photograph of an image of a blind-folded woman holding the scales of justice one evening, when I was walking home past the parliamentary buildings. When I showed Thandiswa this photograph, she told me about her frustration with the ANC's Women's League who, she felt, were blind to the very intimate forms of violence that were being perpetrated against their much less privileged comrades. Thandiswa would, after this conversation, take a series of photographs of derelict open toilets in the field next to her home: one of her neighbours had been raped using this toilet in the middle of the night. She had taken these photographs because she saw the state in its failure to provide safe housing and sanitation, and wanted to speak to the government – to the women in the ANC Women's League – and express her and other women's sense of embodied precarity in Khayelitsha.

Through an ethnographic montage of photographs, films, and participant observation in public protests, pickets and marches, I came to see that the state was imagined and engaged with in myriad ways that span public and private spaces of citizen action; and that these imaginaries corresponded with a sense that the state, in failing to uphold a set of rights around gender, sexuality, education and housing, continued to engender embodied precarity for its citizens despite the provision of ARVs. The photographs and films in which women ‘saw the state’ took me into the more private spaces of their everyday lives, whereas the public marches, pickets, court cases, moved me through more public spaces where men and women brought their bodies to bear witness to the issues they wanted the state to see. The first part of this section engages with the way the women in the core group ‘saw the state’. The second part moves out in scale to explore the implications of these broader concerns on the forms of activism and activist organisations that were most visible in my ethnography as I observed how people ‘spoke to the state’.

7.2.1. “It was kind of like amazing, the president passing by my house”: Seeing the State



Figure 7.2. Illegal electricity wires
(Source: Yandisa, 2011)



Figure 7.3. Illegal electricity wires
(Source: Yandisa, 2011)

Walking through Nkanani one day, Yandisa pointed to the sandals on my feet and told me to wear tougher shoes. By way of explanation, she pointed down to the ground we were standing on. It took me a bit of time before I saw the cables; they were camouflaged by sand and snaked along the gravel road. In some places the flex had been worn down by car tyres, the sun or people’s shoes, and tiny wires bundled out into the sand. My eyes adjusted to reading the sand and I learnt to discern the character of the cables quickly enough to miss walking over the live wires; I also started wearing thick rubber-soled shoes. I was privileged to be able to purchase this degree of safety. Miriam, who lived two-minutes’ walk from Yandisa’s home, told me about the neighbour who lived in the house between them. Her child had gone out in the middle of a thunderstorm to collect water from the tap shared by all of Nkanani’s residents. On the way to the tap the child had stepped on one of these worn-down cables, screaming in shock; when the mother ran out to pull him away, she was electrocuted. The neighbours rushed out to try and help her, but she really needed

emergency medical attention and by the time the sluggish ambulance had arrived, she had died. The government refused to sufficiently subsidise electricity costs through its national company, Eskom, and these accounts spoke to the cost of the state's absence in the presence of these wires: electricity was too expensive for most people in Khayelitsha to afford and so some residents chose to pay people to siphon illegal electricity lines away from the neighbouring wealthier suburb (Somerset West) into their homes. Illegal electricity, however, came at a cost that was experienced by everyone who was connected – often not by choice – along the winding routes that these lines followed across their roofs, along their roads, and sometimes under their feet.



Figure 7.4. Children playing under illegal electricity wires (Source: Zama, 2011)

The first and second photographs above were taken by Yandisa, and show the work that has gone into illegally re-routing electricity from Somerset West into Khayelitsha. The third photograph on the left hand side, taken by Zama, is of her sister's daughter and friend playing in her garden. She had taken the photograph to show the proximity of the illegal electricity lines to her home, and therefore to her and her sister's children's playing area.



Figure 7.5. Waiting for the President (Source: Sibongile, 2011)

There were also many photographs in which people saw the state in large piles of rubbish that collected in the roads, and siphoned around people's homes. Sibongile had, for example, taken a series of photographs (left and below) in which she had 'seen the state' in the open field just over the road from her home. Through these photographs she told me about

President Zuma's visit to her neighbourhood, as part of the ANC's election campaign. Over the course of many photographs, I watched an unfolding picture in which two different imaginaries of the state ran alongside each other. The first imaginary of seeing the state was, quite literally, of seeing President Zuma arriving to speak to a group of supporters at the rally. In these photographs, we see, first, the supporters waiting for his arrival; this is followed by a set of photographs of bodyguards surrounding President Zuma as he walked to the stage to, eventually, address the assembled supporters. Sibongile watched this visit unfold with her two children, all watching this spectacle from a distance and recording it with her camera. She said,



Figure 7.6. The crowds gather (Source: Sibongile, 2011)



Figure 7.7. The President arrives (Source: Sibongile, 2011)



Figure 7.8. The President is introduced (Source: Sibongile, 2011)



Figure 7.9. The rubbish is burned (Source: Sibongile, 2011).

every week.”

“These are the pictures I took when Zuma came. My street actually. He passed by my house. I was standing by the gate. It was kind of like amazing, the president passing by my house. I couldn’t capture a full picture of him, you know everyone coming to see the president” (Sibongile, 2011).

Her photographs captured another powerful picture of the state, however, as she pointed to the large open rubbish dump that featured in the foreground of the photographs that she had taken documenting President Zuma’s visit. She explained to me that the municipality had stopped collecting rubbish from her neighbourhood, and so she and her neighbours had started piling their rubbish on this site during the week. Each Saturday they would burn the rubbish in the morning, but on this day they had postponed the fire until President Zuma left because the smoke would have sullied the slick preparations. Sibongile was excited about President Zuma’s visit, but also angry that the government had not done more to address the economic and racial inequalities she still felt; she pointed to the rubbish heap in these photographs and said, “You see, this is how they expect us to live. What’s that? That’s not right, wena. It’s not good for our children’s health to have all this

rubbish right on the doorstep like this, every day,

I asked Sibongile if she was going to vote in the elections, and she said, quite strongly, “Yes, my grandmother fought hard for the ANC; I will only ever vote for them myself. But I don’t think they will do anything to make my life better.” Seeing these different forms of the state in Sibongile’s photographs suggested to me that people’s concern with issues like sanitation ran alongside an imaginary in which the state was understood to be transitory – to come ‘to my

street', to speak, and then to leave – and ultimately divorced from citizens' everyday struggles. This was most striking in the final photograph, where Sibongile's children are seen sitting on their doorstep, watching the rubbish burn after President Zuma and his supporters had left the open field.



Figure 7.10.
Locked public
toilets (Source:
Yvonne, 2011)

Sibongile's concern with sanitation was reflected in the many photographs of various kinds of public toilets – sometimes broken, or locked – that were scattered around Khayelitsha. Yvonne, for example, took the first photograph on the left hand side; if you look closely, each toilet has a lock on it. Even where public toilets had been constructed, therefore, many people were unable to use them if they had not negotiated with their neighbours to claim – with a lock – a particular cubicle. The women I worked with were particularly concerned about their safety at night



Figure 7.11.
Portable home
toilet (Source:
Yandisa)

because of the numerous accounts of women who were raped when using the toilets. An interim measure, one that was still not acceptable but that was preferable to public toilets, were small portable toilets that had a detachable waste-carrier. Yandisa and Miriam each had one of these toilets in their homes. Yandisa said, showing me the second photograph on the left hand side, that these toilets were an indication

that, "This government does not want dignity for us." Her sentiment was echoed by thousands of other residents in Khayelitsha during my fieldwork and, as discussed below, has become a significant point of activism by an organisation that grew out of TAC in 2008.

On Freedom Day – 27 April, the day of South Africa's first democratic election – this organisation, the Social Justice Coalition (SJC), organised a march in Khayelitsha to demand safe and dignified sanitation. More than 2, 500 people marched on this day, explicitly pointing to the link between the struggle for democracy and the continued struggle for the rights held in the constitution of this new democracy. As we see above, the SJC's call for 'dignified sanitation' was echoed by the people with whom I worked and the photographs they took to speak to the state. The way in which people saw the state, most often in its absence, connected, too with how people then spoke to the state through various forms of citizen action.

7.2.2. 'Every Generation has its Struggle': Speaking to the State

In this sub-section I explore the relationship between the broader set of concerns, discussed above in relation to new generation struggles, and the emergence of a network of activist organisations through which citizens 'spoke to the state'. The new generation struggles that were salient in my fieldwork point to the diffraction of concerns that had previously centred closely around HIV and access to ARVs for those people living with HIV. Now, with ARVs, these concerns relate to the dual struggles around the embodiment of actants (ARVs' side-effects and HIV's viral mutations) and the broader socio-economic context in which people lived their lives on ARVs. I explore the associated forms of citizenship around these new generation struggles below. I suggest that the legacy of citizen action that emerged with the anti-apartheid movement features strongly in the diffracted biosocialities linked to these 'new generations struggles'. Further, I propose that despite these legacies of action and shifts in salient concerns, there is continuity in the way that people embody precarity across these generations of struggle; and further, that HIV-positive citizens continue to hold the state accountable for the extent to which they live precarious lives in post-apartheid South Africa.

7.2.2.1. 'My vote must speak for me': Having Voice

Thandeka's stained thumb pointed to a set of beliefs held by all of the women with whom I worked in the core group. On the whole, they conceived voting as part of an array of citizen practices, like marches and civil disobedience campaigns, that were necessary to make the government listen. Throughout my fieldwork, when people - including those who had not been AIDS activists - spoke about why they were going to vote, the word most often used in their explanation was 'voice'. For example, Witness said, "It is said that your vote is your voice." Bongiwe, similarly, said, "I vote so that I have the right to speak out; the right to voice out my opinion... My vote must speak for me."

Khayelitsha's streets offered a slightly different story. These stories, spray painted on walls or scrawled over posters, reflected a disdain towards the electoral system and towards the leading party. The messages encouraged people to boycott the elections and were on the walls of clinics, streets, taxi ranks and bus shelters. The two images here speak specifically to the conjunction past and present, with their messages written along a wall bordering a street named after one of South Africa's most prominent anti-apartheid activists, and the founder of

the Black Consciousness movement, Steve Biko. Further down the road, near the Magistrate Court – also iconic of a hard-won and, as I discuss below, flawed democratic juridical system – someone had written, “Fuck all politics”. The disdain expressed in the public spaces of Khayelitsha articulated with the deep disillusionment in the government expressed by the people I worked with, particularly around the conditions of life as discussed below.



Figure 7.12. Don't vote, graffiti
(Source: Mills, 2011)



Figure 7.13. Fuck all politics - graffiti. (Source: Mills, 2011)

The frustration held in the graffiti on the walls spoke to a socio-spatial intersection: the history of the struggle for democracy was signified by Steve Biko, and the presence of a faulty but democratically-grounded judicial system, embodied in the Magistrates Court, ran along the walls where people had expressed their frustration with the present political system. This juncture of past and present speaks to a fundamental dissonance that surfaced across my fieldwork in which the rights contained in South Africa's highly respected and sophisticated constitution are constrained by a faulty overburdened socio-economic infrastructure. Like Khayelitsha's streets, and indeed the kinds of lives that people continue to live as they walk them, this infrastructure is inherited in part through apartheid, and falters under the weight of the state's obligations to its citizens.

Among the people who lived in Khayelitsha, but who had not necessarily been AIDS activists, many believed that voting would not generate positive change. Instead, voting was a matter of principle, an assertion of a hard won right that extended beyond the struggle for ARVs to the struggle for democracy. For example, Nozuko said, “I vote because it is free to vote; before Black people never got the chance to vote. They were just decided for. For me it's good to make a contribution by voting”. Also looking towards a history in which voting was limited to the white population, Nomphuthumo said, “I am a South African citizen. Before [under Apartheid] things were hard... Now where we stand, things are better.” Zakhele, a 60 year old man, also spoke about his vote as his voice in South Africa's democracy. He recalled how, during apartheid, his movement around the country had been limited by the Pass Laws, and said, “[I am] voting to have a say and not be limited in where I want to go. If I want to go somewhere I can be able to go.” These accounts reflect a broader set of views among the

larger group of people who did not necessarily have a history of AIDS activism; these views also did not differ across the age or genders of the people in this larger group, and suggest that the presence of South Africa's oppressive history under apartheid continues to compel people to assert their right to vote as a condition of democracy. Voting, for people in this group, it seemed, was less about a way of shaping particular kinds of governance in the future and more about a historically driven assertion of democratic governance in general.

Thobani, as you may recall from Chapter Five and his participation in MSF's ten year anniversary, reflected on voting in his 2011 body map; he spoke about this bifurcation where voting is a means to assert one's right in a democracy but that it does not lead to the fulfilment of obligations – promises – by the government. He says, "You see I'm told to vote to obtain my rights ... but that's just what I've not obtained yet." Sindiswa, who had worked with Thobani and set up one of TAC's branches in her home district in the Eastern Cape, similarly reflects a cynicism in the government's capacity to fulfil its responsibilities, saying, "I vote to keep my country, my government... But I feel that my party does not meet my needs." Like Thobani and Sindiswa, many of the people I worked with believed that voting was an acknowledgement of South Africa's historical legacy and its transition to democracy, but the elections were not viewed by the people I worked with as a way to make the government listen. This sense of 'looking back' and asserting a democratic right when voting differed from other forms of citizen action I observed; these more direct forms of engagement with the state seemed to 'look forward' with an aim to speaking so loudly that the government would be compelled to listen.

When we spoke about specific articulations of 'voice' that were necessary to make the government listen, it was collective public action, including strikes and marches, that were described as the key mechanisms for 'showing a fist' to the government. Ntombentsha is a 30-year-old HIV-positive woman who echoed the majority of participants' assertions on how to make the government listen when she said, "People strike, burn tyres, or going to parliament with posters... When people toyi toyi, the government ends up responding to them" (Ntombentsha, 2011). Toyi toyi, as way to express discontent in public spaces, echoes activist strategies under apartheid; when challenged by the apartheid police, the activists would argue that they were simply singing and dancing. Because the songs were predominantly sung in local languages and not in English, the apartheid police did not understand the political content and were unable to justify intervention. Toyi toying and amended protest songs were also characteristic of the marches that TAC organised to challenge the post-apartheid

government, especially during the height of the government's AIDS denialism. *Toyi toyi* as a form of collective action, and a way to speak to the state, sustained its anti-apartheid legacy in the marches I observed and participated in during my fieldwork. As Noncedo, a 47-year-old HIV-positive woman who also worked at *uYaphi*, notes, "In this time it's like those old days ... where people were burning tyres. You see, we are going back to the past because every time we want the government to listen we have to do action instead of just talking, you need to show a fist!"

7.2.2.4. "You need to show a fist": Between Having Voice and Being Heard

"It's strike season," said Marcus, Equal Treatment's (ET) editor, as the sound of the protesters on Adderley street filtered up the five flights of stairs to our open-plan and – in the heat of March 2011 – open-windowed work space in TAC's national office in Cape Town. This was not an acerbic dismissal but an accurate observation that spoke to the timing and nature of collective action through which citizens spoke to the state. Strike season, in 2011, took place against a larger backdrop with two salient political processes unfolding in the heat of South Africa's summer. These were, first, the Minister of Finance's annual budget speech in February and second, the Municipal Elections in May. In congruence with Marcus's perception of 'strike season' we were, at the moment I heard the strike unfolding downstairs, working on a series of articles of the next ET issue to explore the implications, including strikes, of the budget speech that stipulated greater stringency for already overburdened doctors and underpaid nurses in the public health sector.

Hearing the sounds of the protest filtering up to our office, I looked out of the window and saw a sea of red umbrellas – an international signifier of sex worker rights. I flew down the flights of stairs to join the marchers as they rounded the corner of Adderley Street, just below parliament, and started walking up Wale Street to the Provincial Government's offices. The protesters were marching to deliver a memorandum calling on the government to address police brutality against sex workers.

In South Africa, sex work continues to be criminalised and sex workers, particularly those working in public spaces like streets, are exposed to arbitrary violence by the state. In this case, the protesters were challenging the Provincial Government to address brutality exerted through its mechanisms of control, as police 'disciplined' sex workers' bodies with arbitrary arrests, physical violence and rape. It was striking to see how, as the marchers delivered their

memorandum to the Provincial government, the building was flanked by policemen; the entrance to this physical space of the state was guarded by the same ‘arms’ of the state that had brutally violated the spaces of citizen’s bodies. This is an example of biopolitical precarity as the state not only failed to protect groups differentially exposed to violence, but actively perpetrated violence through these forms of ‘punishment’. The policemen stood at the top of the stairs, legs apart, arms crossed, sniggering at the marchers as we stood below them.

The protesters may have been precariously positioned on the street, without much possibility of speaking directly to key officials in the Provincial Department, but they refused to be silenced. Toyi toying with placards that said, “My body, my rights” and “Legalise sex work now”, about two hundred protesters sang,

My mother was a kitchen girl
my father was a garden boy
that’s why I’m an feminist.

In the course of my life and fieldwork in South Africa I had heard many different endings to that chant including, “that’s why I’m an freedom fighter; that’s why I’m a communist; that’s why I’m an AIDS activist”. The mutable final line brings South Africa’s history of apartheid into the present; it links the range of contemporary struggles to the legacy of structural violence exerted by the apartheid government through its legislative infrastructure in which Black South African men and women were denigrated, stripped of rights, referred to as children – garden boys and kitchen girls. This refrain, and indeed the marches I participated in, indicates a fluidity that draws past performance into the present; we see in the refrain and, as I discuss below, in the ways that citizens performatively ‘show a fist’ to the post-apartheid government, that anti-apartheid resistance tactics have been reconstituted and re-performed.

In addition to performatively constituting contemporary citizen practices by drawing on a gamut of anti-apartheid songs, dances, and other resistance strategies, South Africa’s history was drawn into the present in ways that suggested democracy was not apartheid’s antithesis. The legacy of state violence, wrought by police, transects – in this case – the apartheid and anti-apartheid state, suggesting continuities in biopolitical precarity for South Africans who are criminalised by the law in different ways, but with similar implications for their embodied precarity. This case demonstrates how state violence follows an absence of rights across political dispensations, that precarity is experienced through the body, and that citizens use their bodies to make their precarity visible through marching, singing, dancing. I suggest,

therefore, that biopolitical precarity, embodiment and performativity exist in a dynamic relationship with each other and come together as a form of embodied citizenship.

A broad coalition of activist organisations were represented among the protesters at the sex worker march, and included Sonke Gender Justice, the Sex Worker Advocacy and Education Task Force, the Triangle Project, TAC and the SJC. I had come to recognise the same network of organisations at most of the marches and protests I attended during my fieldwork. For example, a month earlier, in January, I had joined many of these people outside parliament calling on the government to make South Africa safer for women, and just two weeks prior to this march, many of us had been in Khayelitsha's Magistrate Court to attend a trial of nine men accused of killing Zoliswa Nkoyana because she was a lesbian. It was noteworthy that a consistent network of activists and activist organisations participated in a wide-ranging set of citizen actions. This would have been unremarkable just three years prior to my fieldwork, when we claimed public spaces like the streets, courts and even international conferences to call for the then Health Minister's dismissal and for the President to scale up the provision of ARVs. However, in 2010 and 2011, although almost all the marches were strongly supported by TAC activists, none of the marches were about HIV or access to treatment.

With the political commitment evinced by President Zuma in 2009 to rapidly scale up the provision of ARVs, there was a corresponding change in the activist landscape as TAC's primary role in the struggle for ARVs shifted. What could be described as 'TAC's success' also created what was described to me by members of TAC at the time as 'an identity crisis'. The plurality of activist struggles that emerged in the wake of TAC's activism is perhaps also an indication of TAC's success. Similarly, it was evident to me, working with TAC on the Equal Treatment magazine, that there had been an internal reorientation in TAC's advocacy agenda away from the primary goal of ensuring access to ARVs. In my fieldwork, I observed how TAC's advocacy also started to engage with some of the new generation struggles that I describe above, as we realised through our conversation with members of TAC's branches across the country that TAC's members were increasingly struggling with side effects and treatment fatigue. As I discuss in greater detail in the next chapter, TAC continues to advocate on legislative reforms that would better enable people to access medicine and to access better medicines at that by calling for National Health Insurance and for changes to South Africa's Patent Laws. Further, during my fieldwork it was evident that although TAC was not initiating public actions, TAC and its members were participating in public spaces to articulate this broader set of concerns within this network of activist organisations.

Both the SJC and Equal Education (EE) were visible and powerful actors within this network. During my fieldwork, EE seemed to have the largest voice as a social movement in the wake of TAC's powerful activism in the previous decade. EE was formed in 2008 by a group of activists linked to TAC, even initially functioning from TAC's offices until it had become a formal organisation with sufficient funding to run independently. The largest march that took place during my fieldwork was organized by EE in March 2011: over 20, 000 community members, learners, parents and activists marched on parliament demanding that the Minister of Basic Education adopt Minimum Norms and Standards for School Infrastructure. Although organisations like the SJC and EE branched out from TAC, the T-shirts emblazoned on the school children's bodies at this march suggested, to me at least, that perhaps a quiet line had been drawn in the sand where the urgency of AIDS therapies had been supplanted by 'new generation struggles', in this case, access to equitable education. The T-shirts read, Every Generation Has Its Struggle.

7.3. Conclusion

I am calling for us to embrace a more complete imagination of the citizen; someone with a lifestyle, with a history [...] someone who knows things and has a capacity to make decisions. If we could elevate that discourse of citizenship then we could revive the political from the decline into which it has fallen in recent years (Sheila Jasanoff, cited in Leach, Scoones and Wynne, 2005: 217).

When I speak about the sensate state, I am referring to two facets that connect to the dimensions of my research focus. The first facet relates to how people embody and make sense of the government in relation to their lives and bodies; in this respect, this chapter explores the myriad ways that the state's presence was felt very directly in people's lives: in the 'new generation struggles' of ARV medicines that were photographed in bedside tables, or next to the television; in the bruised bodies of sex workers who had been violated by the police; in the physically unbearable accumulation of waste in portable toilets when the municipal truck failed to arrive on the much anticipated Tuesday morning to collect and replace the containers. The second facet is linked to the first, as people found ways to 'act up' and on the state through a range of citizen practices in order to 'raise a fist' and compel the government to listen to their concerns around these 'new generation struggles' linked to newer medicines, physical safety and improved sanitation. In this respect, as ARVs became

more available, activist struggles shifted to encompass the contextual conditions in which people live. I describe these emergent responses to the dual character of the 'new generation struggles' as diffracted biosocialities. I conclude below and in the next chapter that this concept highlights the limits of agency in historic readings of biopolitics as the state and its citizens are porously networked into an assemblage they are both only partially to navigate.

By moving away from a governmentality approach that considers how the state exerts control in and through people's and population's bodies, it can become possible to explore how people themselves conceptualise and strategically navigate their relationship with the state. In working to understand how people make sense of the state through various methods like participatory photography, I was trying to understand biopolitics from a different angle. Reflecting on fieldwork in Bihar, Jharkhand and West Bengal, Corbridge (2005) similarly sought to understand how different actors came to see the state and the different pathways they followed when engaging with the state.²⁴ He writes that, "We are used to the idea of the state seeing its population or citizenry. Visuality is at the heart of many theories of power and governmentality" (2005: 15). He goes on to describe, in much more detail than I can include here, how the state conditions the mechanisms through which governmentality operates in citizens' lives; that even when slightly less directly viewed as the state, these mechanisms – the health system, for example – still function as a way to discipline and control the vitality of bodies (through punishments meted against so-called 'defaulters' for failing to adhere to their ARVs, for example).

He does not look, in the way that I did in my research, at how vitality is not only managed through these mechanisms but also rendered precarious, as Butler (2004) and Agamben (2005) show, when certain populations are differentially exposed to violence without protection from the state. In the case of this ethnography, how a population of predominantly poor, Black, HIV-positive people are exposed to the threat of premature death, and the embodied violence of AIDS-related illnesses as they accrete to death, because the state fails to provide life-sustaining AIDS therapies.

I found that 'seeing the state' is a layered sensory process in which people bring their bodies, their voices, their sight, into their relationship with a porous state in very different ways

²⁴ Just as the activists with whom I engaged in my fieldwork formed and solidified social networks that then enabled them to access a range of social and economic resources (although not without discontent, as we see in Chapter Five and the women's sense that their 'HIV was being exploited') to mitigate against their precarity, so too did the women in eastern India draw on non-state networks to access resources to secure their livelihoods.

through performance, across a trajectory of political engagement spanning the apartheid and post-apartheid eras. Further, I found that states of citizenship are forged through shifting imaginaries of the state as individuals' embodied precarity changed over time. I discussed some of these dynamics in relation to Anamnesis and space in the previous chapter, and continued to explore these dynamics in relation to new generation struggles and biosocial diffraction in the post-apartheid era in this chapter. I suggest that not only does the state make different kinds of citizenship possible, but that different kinds of citizenship, as they are embodied and performed, act on different kinds of states. I explore how everyday citizenship is embodied in the quieter and more private spaces of individuals' lives alongside the public, and more frequently theorised, spaces of collective citizen action performed through pickets, protests and marches. To this end, this chapter connects with Whyte's (2009) emphasis on the importance of analysing the economic and political bases of health as they are embedded in everyday life.

Further, as I propose across this thesis, biopolitics is not a uni-directional and linear relationship between the state and citizen, but a relationship that is shaped by these actors as they are assembled in a network that includes actants (like HIV and ARVs) and global and regional actors (like the WHO and BRICS). Therefore, not only is the biopolitical reach of the state constrained by this network, as I go on to discuss in the following chapter, but the women with whom I worked underlined the myriad ways in which they, too, acted in and through this network to compel the government to provide ARVs and other essential resources to sustain their lives. Further, as we see in this chapter and also in the accounts of frustration by the women working with *uYaphi*, the extent to which women 'speak to the state' through this network also reflects the degree to which their very actions in this network are precarious; or, put differently, we see how biopolitical precarity is networked into the permeable body.

There is an underlying political logic to the argument I make for bringing the political and embodied facets of my research together in this and the following chapter through the concept of biopolitical precarity. The relationship between people's lives and the state is evident in democratic systems because here the vitality of the state is clearly tied to that of the population it governs. As we see, however, with current protests against Turkey's Prime Minister and the recent mining strikes against the South African government's collusion with corporate interests, democracy is not an end-point in the struggle for rights. This was most pertinently captured for me in my fieldwork by Yvonne's mother. She had fought for democracy, and lost her husband in the course of this struggle. Yet, when she learnt she was

HIV-positive, her biopolitical relationship with the post-apartheid government was called into focus as she realised that here, again, she would need to fight for her right to life. In their work as activists, the women I worked with brought their bodies into public spaces. They made their embodied precarity visible to the government through their intimate affidavits bearing witness to their children's deaths and their own precarious lives; through their permission to have their lives, and their embodied poverty, photographed and exhibited globally; through their powerful body maps; through their testimonies of grief in TAC's court cases to compel global pharmaceutical companies to reduce the cost of essential AIDS medicines. To this end, women were fundamentally networked into a global assemblage of actors through their actions as citizens, in multiple public fora, and for shifting biopolitical struggles including the struggle for democracy during apartheid and the struggle for AIDS biomedicine in the post-apartheid era.

However, and herein lies the first of the two underlying political arguments I wish to make: the women with whom I worked were not entirely able to control how their voices, their stories, their images, were used in this assemblage. This is most evident in the case of Thandeka's photograph, an visual icon of a poor Black woman's struggle to access medicines that would, for future generations, prevent what she had herself experienced: vertical transmission of HIV through to her child, because she could not access PMTCT. I met Thandeka and her daughter through this image years before I met her in person, before I saw Thandeka's face and could see the pride with which she looked at the face of her younger self and child in this image. Therefore, I argue that women's socialities forged through this history of activism were not only a very powerful indicator of their agency as they acted up on the networks of actors that governed access to medicines that would save their lives. Their accounts, their lives and relationships, also came to take on a disembodied life as actors in this network. Given the nature of my fieldwork with TAC, and with women who had worked in TAC, this was most evident as activist organisations like TAC and its partners, mobilised these women's stories in the name of the post-apartheid nation's right to life. I observed this too, for instance, in earlier research on the mobilisation of women's narratives for national healing in the Truth and Reconciliation Commission (TRC) (Gobodo-Madikizela, Ross, Mills and Peace, 2005), and learnt of the extent to which it distorted women's accounts to reflect only their sexual precarity and not their political agency (Ross, 2003).

In this thesis, I found that women's stories were disembodied as they moved out from their sight and into virtual spaces online, or into exhibitions on the other side of the world in order to generate awareness around the struggle for ARVs, but also to generate income for those

people and organisations using the images. Women became increasingly distant, in this network, from stories they told and that they and then others sold. This is further underlined by the women's assertion that their HIV is 'exploited' by the so-called 'women's empowerment program' through which they earn a meagre income selling paper mâché bowls to much wealthier people, also on the other side of the world, or at least in South African homes with walls made from bricks and not from corrugated iron sheets and cardboard boxes. In this chapter I referred to the visual processes of my fieldwork because it was principally through photographs that I came to understand how women themselves 'made sense' of the state, without my own interpretations interrupting, extracting or mediating their narratives. I do, of course, analyse these accounts, but hopefully with sufficient transparency.

The second argument builds on the first: women's ability to mediate the networks into which their lives are woven points to the discursive distance that is promulgated by actors in this network in order to distance themselves from the very real and embodied implications of their policies. In this chapter and the next, we see that citizenship practices have diffracted and expanded beyond the initial assertions of biological and therapeutic citizenship at the height of AIDS activism in South Africa. Butler (2004a) discusses the way in which people become de-faced through governmentality, separated from the disciplining processes that produce and regulate docile bodies. I suggest that there is a space between this conception of biopolitics that 'acts down' and the 'active citizen' that 'acts up'. This is evident in the diffracted forms of biosociality that reflect the broader set of claims that extend beyond the focus on AIDS medicines to include concerns around housing, sanitation and security. It is perhaps most pertinently seen in the space between having worked to access first and second line ARVs in South Africa, and yet still having life curtailed by the government's failure to reformulate its patent legislation (as discussed in the following chapter) in order to procure and provide third line ARVs. I suggest, however, that the government's capacity to respond to these claims is, in part, shaped by the extent to which it is networked into regional economic blocs (like BRICS) and global actors (like the WTO and EU-India trade agreements). Thus, the extent to which citizens can act on the state, and to which the state can intervene in the vitality of its citizens, is constrained by the fact that not only is the state porous in relation to citizens, but also in relation to other regional and international actors. I turn, therefore, to the final chapter in which I trace the state and these women's capacity to secure their vitality within this assemblage, and indicate how these global actors are, in turn, implicated in women's embodied precarity.

8. Therapeutic Governance

As I argue through my thesis and conclude in this final ethnographic chapter, women's embodied precarity is linked to the network of actors that coalesce in a global assemblage that governs AIDS technologies. Once on ARVs, women's lives are not simply tied into the will or capacity of the state to provide these medicines. Instead, access to new biomedical technologies, ones that have fewer side effects and enable longer life, come to be embodied by women as a discursive outcome of an assemblage of globally dispersed and connected laboratory experiments and production lines, international economic agreements, national legislature, public health care systems and social relationships. In this chapter I focus specifically on ARVs as actants and on the global assemblage that governs these technologies. By looking at a network of actors across this assemblage, I trace the various routes that these actants travel to become animate and intra-act with HIV in the bodies of the women I worked with. Thus, moving away from Foucault's (1978) notion of biopolitics, and beyond the previous chapter's discussion of imaginaries of the state, I explore how the state of the body and the body of the state are part of a transcendent assemblage that they are only partially able to negotiate.

In this chapter I move out from South Africa to trace this assemblage across the ocean into Brazil (and then beyond) because the two states have an important regional relationship and historic dynamic, as outlined in Chapter One. First, they faced each other as they moved, together, into a new democracy in the 1980s and early 1990s with a hopeful constitution that was actively worded to redress the inequalities wrought through their former governments. Second, they turned away from each other as Brazil followed a route of actively working to ensure the rights of HIV-positive citizens to life by providing ARVs, in contrast with South Africa, as the government obstructed citizens' access to ARVs. Looking out from South Africa, I was aware of the construction – by activists – of Brazil as the 'activist state'. I therefore undertook research in Brazil to understand the evolution of the state's response to HIV-positive citizens. I was challenged, again, to reconfigure my initial assumptions about Brazil as an 'activist state'. Importantly, this pointed to the third phase in a dynamic role between Brazil and South Africa as they engage through regional coalitions like BRICS (Brazil, Russia, India, China and South Africa) with other countries, like India. These coalitions are networked around the governance of AIDS medicines as Brazil and India have navigated complex international legislation around intellectual property rights in order to protect their domestic

pharmaceutical industry, and in the case of Brazil, to ensure that it is able to import the (7 of 15) ARVs that are not locally produced.

To this end, I have structured this chapter over three sections to move from looking at the relationship between Brazil and South Africa, to a deeper understanding of therapeutic biopolitics in Brazil, and finally, to locate both countries in a regional and international assemblage that shapes the development and distribution of these medicines. In the first section I explore the tension between neoliberal reforms and redistributive politics, and some of the implications of this tension in the manifestation of these policies for people's health in Brazil. The second section debunks the construction of Brazil, in contrast to South Africa, as the 'activist state', by exploring how activists worked with the newly democratic government to co-construct the juridical infrastructure governing access to AIDS therapies. Thereafter, I contrast the 'new generation struggles' linked to AIDS medicines I found in South Africa with those I observed in Brazil, and consider their implications for adherence and biosocial diffraction. The final section extends the argument that biopolitical precarity is networked into the permeable body by tracing the threads linking the ARV actant into a global assemblage, from under the skin of the body, across porous national borders and into regional and global networks that govern the development and distribution of AIDS medicines.

8.1. Brazil's Rising Power and the Tide of Neoliberal Reform

The street outside Hospital Universitário Osvaldo Cruz in Boa Vista, Recife, was lined with buses bearing number plates from towns in Sertão; the semi-arid interior in the western most part of Pernambuco, a province in Brazil that is home to 8, 931, 028 people.²⁵ Many people, my friend Rafaela Ortiz explained to me, travelled between one and two days to come in from the interior to access the hospital's tertiary health services. Renato Athias, an anthropologist I met in Recife, confirmed Rafaela's observation. Having worked with indigenous groups (most notably with the Pankararu Indians) in the Amazon region of Pernambuco's interior, he noted the absence of secondary and tertiary health care – provided by Brazil's Unified Health Care System, Sistema Único de Saúde (SUS) – outside Pernambuco's urban hubs (see Cornwall and Shankland, 2008; Shankland and Hasenclever, 2011). In addition to the limited reach of tertiary health care in the province, HIV activists in Recife were concerned about the encroaching privatisation of the city's public hospitals. The walls of this particular hospital bore witness to

²⁵ http://www.ibge.gov.br/home/estatistica/populacao/estimativa2012/estimativa_tcu.shtm; accessed April 2013.

some of the more visible implications of public-private partnerships. The municipal government had incrementally withdrawn funding from the hospital's maintenance budget with the intention of compelling private health insurance companies to start investing more directly in the hospital's running costs; Recife's humidity had crept into the old building and slowly peeled the red paint off its walls, leaving a peach-stained concrete memory of its former façade. A small newer-looking building, with bare brick walls, ran behind the hospital's main entrance. It was here that HIV-positive people were cared for by a team of social workers, nurses, specialist doctors and, at times, complementary therapists like acupuncturists.

In Khayelitsha, I had come to know the clinics and their long queues viscerally; my body, like those of the women I worked with, ached at the end of the days we spent in the clinic moving from one long queue to another, often standing but sometimes sitting on wooden benches, in the monthly ritual to get these hard-to-swallow but hard-won medicines. In this specialist clinic in Recife, about 20 comfortably spaced chairs lined the small reception area and only half of them were used by patients at any one time; even the architecture of the clinic spoke to the difference between South Africa and Brazil's HIV epidemics. The clinic was located outside the main hospital, providing dedicated care to HIV-positive people in a very much smaller building than any of the community health centres or clinics that provided integrated care to all of Khayelitsha's residents.

Epidemiologists in 1988 would have been surprised to see each country's dramatically different HIV profile in 2011; at that time, Brazil had the second highest number of reported HIV cases in the world (after the United States) (2009) compared to South Africa, which had an HIV prevalence of just under 1% (Brasil, 1988). Now, Brazil's prevalence remains below 1% and South Africa has an HIV prevalence of 18% and is home to the largest number of people living with HIV in any one country in the world (Brazil, 2012; UNAIDS, 2012).

The politics of Brazil's publicly-funded, universal, rights-based health system needs to be contextualised against the backdrop of Brazil's recent emergence as an economic power, perhaps most visibly signified by BRICS and its alliance with these other powerful economies. SUS came to life in Brazil, through its "citizens' constitution" at a time when international neoliberal reforms spurred the marketisation of health, particularly in Latin America (Cornwall and Shankland, 2008). Access to health care through SUS reflected a broader national commitment to social welfare in Brazil. Here too, however, there is a tension between

neoliberal reform and socio-economic equity. Committed to addressing the structural dynamics of poverty, the administrations of Fernando Henrique Cardoso (1995 – 2002) and Luiz Inácio Lula da Silva (2003 – 2011) introduced a raft of social welfare policies that expanded Brazil's conditional cash transfer (CCT) programmes (Hall, 2006, 2008).

One such policy, Bolsa Família, forms part of the Fome Zero federal assistance programme and was the principal source of support for Gabriela, an HIV-positive woman I first met in 2009, and whom I came to know over the course of my subsequent fieldwork. She moved from Floresta, a small city in Pernambuco's interior, to Recife in 1997 and has two children, 8 and 12 years old. Gabriela has been able to send her children to school in Recife because of the education stipend she receives through the Bolsa Família program. Bolsa Família has four sub-programmes (with stipends for school attendance, maternal nutrition, food supplements and a domestic gas subsidy) and since 2003, government spending on this programme has risen to one-third of the national social assistance budget (Hall, 2008).

Brazil's social welfare policies have been recognised internationally as an indication of Brazil's commitment to equality and its citizens' wellbeing, not unlike the characterisation of Brazil's response to HIV. This may account for why, in March 2013, the World Bank Group and United Nations announced that they would adopt Brazil's Bolsa Família programme as an international model for social inclusion. World Bank President, Jim Yong Kim, said,

This agreement ... recognizes Brazil as a global leader in reducing poverty and inequality. Progress made during the last decade has been remarkable and the world can learn a lot from the Brazilian experience. In Brazil, the percentage of the population living under extreme poverty has fallen from about 20 percent in the early 1990s to about 7 percent in recent years... Boosting shared prosperity and equality go hand in hand. Brazil has demonstrated that solid economic policies coupled with social responsibility are not only possible but desirable. And that growing while at the same time reducing inequality is an attainable goal (Jim Yong Kim, 4 March 2013).²⁶

With this rationale, the World Bank is supporting the implementation of CCT systems in 60 countries around the world, including China and South Africa; in South Africa, the initiative will focus on delivering health services in townships. Although this programme is a flagship for CCT programs in other parts of the world, its implementation was strongly critiqued among the people with whom I worked in Brazil.

²⁶ <http://www.worldbank.org/en/news/speech/2013/03/05/memorandum-understanding-signing-knowledge-innovation-initiative-brazil-statement-world-bank-group-president-jim-yong-kim>; accessed March 2013.

These critiques were also borne out through my fieldwork as I saw the extent of inequality that people embodied in their homes and lives in Recife. Like Cape Town, historically entrenched socio-economic inequality was etched into Recife's cityscape; but unlike Cape Town, where race and class are layered into and also separated through space, Recife's poverty was defiantly visible. People had, for example, made their homes in some of the abandoned buildings that stood next to glittering skyscrapers along the long stretches of beach in the wealthier sections of the city like Boa Vista; more often, though, people built their homes in the small wrinkles of land between high rise buildings or lived in large favelas that were located, like Khayelitsha, on the periphery of Recife's historic centre. Sometimes even solid ground was difficult to find; on my bus journey across Bacia Portuaria, I learnt to mark the rise and fall of the tide according to the length of exposed wooden legs holding up the small homes that had been built on the side of the estuary. The sense that the state was receding from people's lives, becoming less accountable to its citizens and more entrained in international neoliberal networks, surfaced frequently in my conversations with medical professionals, social workers and activists.

"I belong to another generation," said Dr Inês Mendes, a paediatric doctor working at a renowned maternity hospital that also provides specialised care for HIV-positive parents and children in Recife. Pointing to the specialist HIV unit, she said,

There are three doctors here and we need to attend to 1, 200 people [per month]; it's just too much for us. The government doesn't value our work anymore... It's not like the old days (Inês, 2011).

Mariana Rossi, a social worker and professor in Social Development, similarly pointed out the government's failure to provide the necessary resources to address social inequality in Recife. Describing the role of social workers as the "interface between medical systems and social justice and human rights", Mariana recounted her memories of Brazil's transition to democracy in the 1980s and the hope she felt for Brazil's future as the democratically elected government came into power. Brazil's political transition, she explained, took place alongside an epistemological transition in the field of social work. Prompted by the politics of the centre-left party, the *Partido dos Trabalhadores* (Workers' Party), the clinical social work paradigm shifted from conceptualising the individual as the problem to a Marxist paradigm that engages the structures in which individuals are located. However, echoing Dr Mendes's observation above, Rossi said that Brazil's government no longer had the interests of its citizens at the heart of its policies. She explained that rather than addressing structural inequality, the state

had adopted a neoliberal logic in which wellbeing was constructed as an individual's responsibility. This, she said, was a legacy of the preceding administration: "Lula let people down: he compromised to accommodate the interests of the other political parties... I am the government. I pay taxes, I want to benefit. But not only me – all Brazilians."

Rafaela Ortiz, a prominent feminist activist and educator, also spoke about the tension between the Marxist principles of President Lula and now Dilma Rousseff's Workers Party and the neoliberal agenda that had emerged through 'compromises' with centre and centre-right parties in Brazil's government. In contrast with the World Bank leader's statement above, the people with whom I worked in Brazil did not believe that it was possible to reconcile 'solid [neoliberal] economic policies' with economic equality. They felt that there was an inherent trade-off in the quality of public services as they became tied into economic reforms that, for example, encouraged the proliferation of public-private partnerships in the health sector. Ortiz explained that the social assistance programs, although founded on the principle of economic redistribution to flatten stark economic hierarchies, have become co-opted by capitalist logic:

Brazil is among the 10 most unequal countries [in the world]. Recent compensatory policies, such as quotas and policies of income redistribution like Bolsa Família, has undoubtedly changed and is changing the lives of millions of Brazilians who were refused these basic rights. No doubt it is a profound change, but also the neoliberal capitalist logic follows a deepening of its relations and business interests. It is difficult to have full access to justice and social rights amid the capitalist rules (Rafaela, 2011).

The public spaces of Recife bore witness to its residents' discontent, expressed in shorter phrases than Ortiz's quote above, but with a similar bottom line: Marxist principles have been replaced by a capitalist logic and Brazilians are bearing the brunt. One day, when walking back from lunch with Ortiz, Rossi, Gabriela and a number of other people who were participating in a conference on HIV in South Africa and Brazil, I asked about the messages that had been scrawled on the electricity hubs on each building. Ortiz explained that there had been a call by unions across the country – including those linked to universities – to boycott the general election that had taken place five months earlier, in October 2010. The messages said, "TUDO PARA TODOS TOTALMENTE" [Everything to everybody in totality], and echoed those written across bridges, construction sites and other public spaces throughout the city, saying: "LUTE PELO SOCIALISMO" [Fight for socialism]; "VOTAR NAO! REBELAR – SE E JUSTO" [Don't Vote! It is fair to rebel]; and "ELEÇÃO NÃO TRÁ TRANSFORMAÇÃO. BOICOTE!" [Elections don't bring transformation. Boycott!]



Figure 8.1. Don't Vote! It is fair to rebel (Source; Mills, 2011).

Figure 8.3. Elections don't bring transformation (Source: Mills, 2011).

Figure 8.2. Fight for socialism (Source: Mills, 2011).

This sentiment of discontent ran alongside another prevailing concern among health activists in particular that, from my perspective as a South African, seemed to complicate the narrative that Brazil's government was 'abandoning' its citizens in order to follow a neoliberal logic that benefited a few at the expense of many. This parallel concern related to, what I perceived to be, the long-term challenges, emerging from the country's long history of providing AIDS therapies to its citizens. In Brazil, these challenges speak to the kinds of 'new generation' struggles I perceived through my fieldwork in South Africa.

In contrast with South Africa, these struggles were not new in Brazil. They were, as I learnt from activists in *Saúde Para Todos* (SPT), an established and serious issue for people living with HIV and receiving ARVs through Brazil's public health sector. The following section traces the history of activist engagement with the government to access AIDS therapies, and brings this history into the present by exploring some of the struggles people experienced as they embodied AIDS therapies.

8.2. Debunking the 'Activist State'

8.2.1. Evolving AIDS Therapies and Activist Coalitions: A Brief History

The extent to which life is contingent on international actors runs alongside another narrative: people do not simply embody precarity because they are acted 'on' by actants, like HIV, and actors, like national governments or international organisations that regulate a country's, and therefore a citizen's, access to life-sustaining medicines. As the accounts below illustrate, and as I have explored throughout this thesis, people in both Brazil and South Africa have actively engaged with this global assemblage in order to bring ARVs out of laboratories and factories in

places like US and India, into their country, into their public health systems, and into their bodies.

Over the course of numerous conversations, Joao Martinez, a prominent HIV activist and Professor of Mathematics, painted a layered picture of Brazil beyond its narrow narrative as an 'activist state'. Through these conversations, and through his own life story, I learnt about a network of activists who had come together to support and shape the government's response to HIV through its public health system. I trace these stories here, in relation to Joao's own life, to highlight a set of actors within and beyond Brazil's boundaries that assembled to bring ARVs into Joao's body.

Joao recounted how activists from the gay, sex worker, feminist and sanitaria health reform movements formed a broad coalition in the late 1980s and early 1990s to promote equitable access to prevention and treatment services; numerous NGOs emerged from this coalition that, using innovative media tactics, kick-started a high visibility media campaign that promoted HIV awareness and prevention across Brazil, but particularly in the South and Southeast regions where HIV prevalence was highest (Biehl, 2004, 2005; Biehl, 2006). Nunn et al (2012) note the institutional ties between activists and the government over this time, and role of the World Bank loan in formalising these links:

The AIDS movement's ongoing informal partnerships with policy-makers were formalised in the early 1990s, when AIDS activists were asked ... to help draft World Bank loan proposals for AIDS assistance. Brazil's AIDS programme was a well-functioning bureaucracy by the mid-1990s, and the World Bank loans help institutionalise formal partnerships between civil society and the state (2012: 5).

Rafaela and Joao, however, said that although the World Bank loans (particularly the first loan, in 1992, of \$160 million) funded important HIV awareness activities in NGOs, it also meant that the government did not invest enough of its national budget in HIV in the early 1990s. "The loans changed activities by NGOs and the public sector," he said, and went on to clarify that the government initially did not want to invest funding in treatment activities, and instead focussed on prevention. NGOs, in turn, were caught between wanting to source funding through the World Bank by collaborating with the government on its prevention programs, while seeing the emerging availability of medical treatments on an international scale and making the national government similarly see the imperative of sourcing these extremely expensive but life-sustaining medicines. For the people I worked with in Brazil, as in South Africa, these imperatives had direct implications on their ability, or not, to live, and on their

likelihood of transmitting HIV along vertical and horizontal pathways. Joao reflected, for example, on the difficulties he encountered when trying to access AIDS medicines through Sao Paulo's state program after he was diagnosed with HIV in 1989, and his despair as he witnessed his friends, colleagues and lovers die of AIDS in the late 1980s.

The tension between the government's economic reforms and its constitutional commitment to its citizens emerged as a strong theme in my fieldwork. Writing about Brazil and the relationship between biopolitics, AIDS and neoliberalism, Comaroff encapsulates this tension, and says,

it is undeniable that health activism in several parts of the south have proven particularly vexing to states seeking to reconcile the privatization of public services with constitutional empowerment, especially where governments struggle to assert sovereignty against the force of transnational markets and translocal organizations (2007: 2005).

In his ethnography with people living with HIV in Brazil, Biehl (2004, 2005) similarly observes this tension, and suggests that Brazil is an arena where activists are powerfully adept at crafting techniques to maximise equity, particularly linked to accessing AIDS therapies, in a neoliberalising state.

The first breakthrough in HIV therapy fuelled the fervour with which Joao had been mobilising the government through *Pela Vida* to invest in treatment alongside prevention. The breakthrough, in 1987, was marked by the United States' government's approval of retrovir/zidovudine (AZT) – the first drug that was found to successfully inhibit the replication of HIV in patients. It was also found to reduce HIV transmission from mothers to children (Wright, 1986). Sao Paulo, Joao's home at the time, was the first state in Brazil (and the first programme in Latin America) to provide this treatment, and in 1991 the government committed to making the drug available to all Brazilians. The next major medical breakthrough, according to Joao, took place five years later when he attended the 11th International Conference on AIDS in Vancouver, in 1996. It was here that triple therapy was first declared an effective treatment capable of transforming HIV into a chronic and manageable condition. Joao returned to Brazil where he met with the Ministry of Health to discuss the value and viability of providing ARVs to all Brazilians. He recalled how, when he asked whether the cost of providing treatment would be a constraint, he was told, "No, I want your expert knowledge; we will take care of the bill."

Thus began, as he described it, “The Hurricane of Triple Therapy”. The legislative machinery still, however, had to catch up with these therapeutic advances and government mandates. Joao, for example, needed to engage multiple legal processes (up to 1, 250 per month in July/August that year). The courts met each action favourably because, as he said, “The rights of a person could be hurt irreparably [if the state did not provide ARVs].” He describes this legal process as a personal victory, because it had such direct implications on his ability to live: “I won! One week later I had my therapy. Justice that came late would not be useful. You had to get it quickly, or you would die.” Joao’s account emphasises the value of moving beyond the label of Brazil as the ‘activist state’ towards conceptualising Brazil’s actions as enabled through a complex configuration of multiple local, national and international actors. He spoke of his ability to live, his vitality, as an outcome of his engagement with activist networks (including ABIA - Associação Brasileira Interdisciplinar de AIDS - and Grupo Pela Vida) and, in turn, their engagement with the judicial system, particularly its judges, and the various levels of state and federal government that drove Brazil’s HIV policies to keep pace with international developments in medical technologies.

In the following section I look at the ‘treatment gap’ between Brazil and South Africa to explore some of the longer term and embodied ramifications of AIDS therapies. In South Africa, I had come to know about the ‘treatment gap’ as a quantitative assessment of the number of people needing ARVs against the number of people receiving ARVs. In Brazil, the ‘treatment gap’ meant an entirely different thing and perhaps speaks to each country’s very different history with regards to AIDS therapies. When Brazilians referred to a ‘treatment gap’, they meant that they were stopping their medicines for a period in order to have a ‘break’ from the responsibilities entailed in adherence, and from the side effects that some people experienced from the intra-action of ARVs with their bodies.

Although South Africa scaled up treatment services by 75% between 2009 and 2011 (UNAIDS, 2012), and reached its target of providing ARVs to 80% of all those in need in 2012, its historical ‘treatment gap’ is still, as Fassin (2007) reminds us, held in people’s embodied memory of the precarity of their and other’s lives prior to the public provision of ARVs. In Brazil, too, there is a gap between the number of people in need of treatment and the number currently receiving ARVs. Biehl (2004), for example, describes and problematises the international conceptualisation of Brazil as an ‘activist state’ because the government was the first in the developing world to make AIDS therapies available to the ‘registered AIDS cases’. This terminology is important because Biehl, particularly in his later work (2008), describes

how the government's AIDS response, including 'registering AIDS cases', dovetailed with former President Cardoso's efforts to internationalise Brazil's economy. These efforts, argues Biehl (2004; 2008) created 'zones of abandonment' where socio-economically marginalised groups, like transgendered people, transvestites, sex workers and intravenous drug users, were less able to access these public health services than wealthier sections of the population deemed more 'legitimate'. Thus, as I explore in the next section, although medicine may be available in Brazil, the current struggles linked to AIDS therapies extend beyond the country's capacity to produce, procure and provide these medicines through the public health sector.

8.2.2. AIDS Therapies and Diffracted Biosocialities: The Present Tense

Taking me into an examination room in the HIV specialist unit, Dr Mendes opened the door of a floor to ceiling cupboard and gestured at the metal shelves holding hundreds of little cardboard boxes of medicine. They were half-used packs of first and second-line antiretrovirals that her patients had returned to the clinic when they decided to terminate their treatment. Dr Mendes explained to me that, "Sometimes patients stop ARVs because of personal prejudice. There are side effects, sure. But also, people who can read the side effects [on the insert] will have all the side effects."

In contrast with South Africa, a 'treatment gap' in Brazil did not necessarily refer to ARV coverage. Instead, it was another term for an 'ARV holiday' where people stop taking their ARVs for a few weeks, or months. Lucas, for example, recounted to me some of the serious side effects he had experienced from ARVs since starting them in 1997. He had travelled down from his home in Fortaleza, capital of the northeastern province of Ceará, to attend a conference on HIV vaccines. We had both given presentations that morning, and were – at this point – having lunch on the broad steps that led out onto the large garden of this conference centre in Olinda, Recife's much smaller and extremely beautiful neighbour. The previous night we had been out in Olinda's cobbled streets together, watching a procession of giant papier-mâché puppets, marching bands, and dancing troupes to join the rest of the town's small population to celebrate Olinda's formal recognition as a town (on March 12, 1537). It had been a late night of music and dancing, and one that gave me a sense of the kinds of celebrations that took place around Olinda's legendary 'Carnaval of Participation'.²⁷

²⁷ This is a reference to Olinda's historic decision, in 1977, to keep its carnival open and free to all participants, in contrast with Brazil's other extremely popular carnival in Rio de Janeiro.

The principle of participation is the same reason that, according to Rafaela and Joao, the health movement had so successfully mobilized the government to institute SUS through its 'Citizens' Constitution' of 1988 (see Cornwall and Shankland, 2008); and to provide ARVs in 1996 through the Constitution. By 2012, an estimated 490, 000 [430, 000 – 570, 000] people were living with HIV in Brazil (UNAIDS, 2012), and in 2010 the Brazilian government recorded that 200, 000 people received ARVs through the SUS (Brazil, 2012). Lucas is one of the people who make up these official numbers and yet, unofficially, he was at that time on an 'ARV holiday'.

Sitting outside while people milled around during the lunch break, we picked up the conversation we had started the previous night. I spoke about how, at that time in 2011, TAC was concerned that health facilities were using stavudine (d4T) when there were stock-outs of tenofovir (TDF). This followed an update to South Africa's ARV treatment guidelines in 2010 in which TDF replaced d4T, a drug that caused long-term irreversible side effects, but that was more affordable than its alternatives, TDF and AZT.^{28, 29} The issue of access to new ARVs – particularly third line medicines - in Brazil had been raised that morning by a number of Lucas's colleagues. Our presentations, too, had underlined some of the issues I had been finding in my fieldwork and that he had found through the HIV rights organisation he worked with, and that was a partner to SPT, in Fortaleza. We had spoken about the importance of introducing new medical technologies into the public health sector, and the historic role that each of our governments played in negotiating the domestic production and international procurement of these medicines.

Now, sitting in the sun, away from the formal space of presentations and discussions, our conversation moved in halting English but flowed easily with a quieter non-verbal exchange, as we took turns getting up to get each other refills of the black coffee that stung our hands through the thin plastic cups. Putting down his coffee cup and holding my eye, Lucas swivelled his body to face mine and with both of his hands he traced the sharp line of his cheekbones. Then, almost as if he was stroking his face, he made a scooping motion to emphasise his hollowed out cheeks. I got up, nodding my head and, in this non-verbal exchange about lipodystrophy, ran my hands down my legs, shrinking them down in size, and making similar scooping motions to flatten my breasts and buttocks. He stood up, nodding, pointing to his body and showing me where, on his body, he still bore the effects of d4T's lipodystrophy,

²⁸ <http://i-base.info/htb/10195>; accessed April 2013.

²⁹ The patent for AZT, held by GlaxoSmithKline Plc, expired in 2005 and so the reduced price of the generic versions made it more affordable for South Africa to purchase this drug.

pointing to his cheeks again, and also to his round stomach and thin legs. The intra-action of this medicine with his body had, he said, saved his life when he first started ARVs, but had also marked him as HIV-positive to those around him who were able to read the 'marks' of ARVs on people's bodies. He had subsequently moved off d4T, but was concerned about the general damage that ARVs may be quietly wreaking on his body, without him being able to 'see'. Lucas explained that he believed ARVs 'worked' because he was alive, but that they also put his body under strain. He said that he took a break from ARVs, "Not because they don't work. But to give my body a break now and then." Unlike the newer AIDS therapies, the life of d4T – as an actant – was visible on the outside of his body, borne through these kinds of side effects. The quieter lives of newer ARVs, and their possible long-term side effects – like cancer – were harder to identify. This concern was underlined at the conference the next day when a member of the Brazilian Ministry of Health said, "[N]ot only would a therapeutic vaccine reduce the need for ARVs, it could go further towards eradicating side effects: in our country we have increased rates of cancer, psychological effects, lipodystrophy."

Gabriela, who I introduce above, is also an active member of the HIV community with a long history of working to compel the government to provide better health services and newer AIDS medicines to HIV-positive people. With this particular history of activism linked to AIDS medicines, it was perhaps understandable that Rafaela was dismayed to hear that she, too, had taken an 'ARV holiday'. Unlike Lucas, Gabriela had not openly spoken about stopping her treatment, but had told Rafaela in a fit of exasperation at the pressure she felt to 'represent' the movement while also just wanting to, as Rafaela told me, 'get on with living'. Gabriela had just a few days earlier told me about her relationship with Rafaela as we were travelling across Recife after spending the day in meetings with municipal health officials. After initially working with a larger HIV organization in Recife, Gabriela had opted to leave and form a smaller organisation that would be run for and, importantly, by HIV-positive people; Rafaela, at this point, moved from her work with a feminist organisation in Recife to direct her energies, with Gabriela and this team of people, to form an organisation based on the principles of equality and citizenship.

The network of people and organisations I engaged with in my fieldwork were, as far as I could tell, connected through splices of shared politics and fundamentally through their shared relationship with Rafaela, prominent feminist, educator and health activist. The two organisations I came to know best were SOS Corpo and SPT. Rafaela worked in SOS Corpo for just over a decade following Brazil's democratic transition with the intention of harnessing the

opportunities for integrating feminist politics into federal and provincial policy spaces presented by the transitional policy space. Rafaela explained how her vision of the world was shaped, in part, through her work with activists like Gabriela, and with organisations like SPT:

Working for 20 years in the feminist movement gave me the basis for my political and conceptual understanding of the world through the perspective of equality and difference. And education was an important principle of feminism that made me realise the meaning of socialism that I adopt in my political positions. But mostly it was the people who were living with AIDS in Brazil that allowed me to connect my political activism with feminist education. It was the people who were living with AIDS that particularly touched my heart with their struggles and their resistance that gave energy to the movement in Brazil (Rafaela Ortiz).

Gabriela said that it was through working with Rafaela that she had first learnt about her rights as a citizen in Brazil, and that it was with Rafaela that she had started to claim her rights as an HIV-positive citizen in the political spaces of HIV and health care policy.

It is striking, therefore, that her 'holiday' from AIDS medicines coincided with her assertive declaration to another member of the Brazilian Ministry of Health, also at this conference, that, "We can live with HIV, but we need medicine and support to be active citizens." As I discuss in Chapter Five, with respect to the 'new generation' struggles experienced by activists in South Africa, this was not a form of cognitive dissonance in which the private multi-faceted self, struggling with ARVs, becomes split from the public self as an active citizen, advocating for ARVs. Instead, it points to the complexities of AIDS therapies as they come to be embodied by individuals who have, historically, formed part of a larger biosocial coalition based on a shared illness and who have made a set of claims, as therapeutic citizens (Nguyen, 2005), around corresponding treatments. Gabriela and Lucas's accounts resonate with those in Chapter Five as they indicate an ambivalence created by the, at times precarious, intra-action of AIDS therapies with bodies.

On the one hand, as Lucas said, these medicines prevented HIV from replicating in his body, thus 'saving his life'; on the other hand, his body held the memory of d4T's toxicity, visible, still, in his hollow cheeks. It is, perhaps, because Zama's body holds the memory of HIV – and not ARVs – in the 'brown map' on her skin, that 'ARV holidays' were not really considered an option by the women I worked with in South Africa. The 'previous generation's' struggle for ARVs continues to be visible on Zama's skin as a form of embodied Anamnesis. Perhaps, then, the presence of this embodied history of precarity accounts for Zama's insistence on adhering

to her medicines, whereas the more recent ‘new generation struggles’ that Lucas describes may account for his decision to have a ‘treatment gap’.

South African activists, like Zama, referred to Brazil, and the stark reduction in AIDS-mortality rates in the late 1990s following the introduction of ARVs, in order to mobilise Mbeki’s government to provide these medicines. As discussed in the previous chapters, and by ethnographers studying AIDS activism at the time (Robins, 2005, 2006), South African activists drew on discourses of therapeutic citizenship that emphasised bodily sameness and biomedical autonomy. However, my fieldwork in South Africa – a decade after ARVs were introduced by the government – found an emergence of diffracted biosocialities among people who had worked to bring AIDS therapies into the country, and into their bodies. The previous chapters show that the collective assertion of shared vulnerability and bodily sameness (in order to access AIDS therapies) had shifted; at the time of my fieldwork in 2010/11, they included an embodied awareness that AIDS therapies not only animate bodies to sustain life, but they become animate within bodies in variable ways that also include visible, or less visible, side effects. This underlines, as Whyte (2009) similarly argues, the value of engaging with the embodied dimensions of subjectivity that may inform multiple and intersecting citizen practices.

The life of these medicines, and their effect on the vitality of HIV-positive men and women in Brazil and South Africa, is not only an outcome of activist networks and their engagement with the juridical and political infrastructure of each state. It is also contingent on the engagement of governments with international actors that moderate the development and movement of medicines from laboratories, across national borders and into the public health systems of countries, like Brazil and South Africa. Recognising the importance of tracing embodied precarity into this global assemblage, Comaroff similarly asks,

just how useful, in confronting these issues, is the concept of bare life, spoken of in terms of pure subjection and gross biopolitical being, meaningful only as a sign of sovereign power? The question is crucial if we are to take seriously Agamben’s own exhortation to engage in a politics that recuperates civic being. More immediately, it is consequential if we are to make sense of the various ways in which HIV has been politicized and politics biologised (2007: 209).

To this end, I argue below that the possibility of life or the threat of death not only exposes the biopolitical relationship between citizens and the state: it calls attention to the global assemblage into which their vitality is woven, rendering the body of the state and the state of

the body both porous and precarious.

8.3. Between BRICS, Borders and Bodies: The Global Life of AIDS Therapies

It was Brazil's bold effort to secure free access to treatment, including through the use of compulsory licensing, that demonstrated what was previously thought impossible—that a developing country could deliver universal access. The boom in HIV treatment could not have happened without the Indian generic pharmaceutical manufacturers, who now supply an estimated 86% of the total volume of ARV purchases (Michel Sidibé, UNAIDS Executive Director, at the 2011 Meeting of BRICS Health Ministers).

In this section I explore three national actors (Brazil, South Africa and India) as they are networked into regional and international alliances (through BRICS and with the European Union). In particular, I consider how India has gained the title of 'pharmacy of the developing world' by strategically navigating international legislation around intellectual property (IP) and the production of biomedicine through its national juridical infrastructure. These national, regional and international actors assemble around a rapidly changing set of international laws that govern the development and distribution of biomedicines like ARVs, and have implications for the people I worked with in South Africa. I therefore consider a set of current policy challenges for South Africa and, in looking at the dynamics of this global assemblage for access to ARVs, I outline the biopolitical implications of these policies for HIV-positive people whose vitality is precariously networked into this assemblage. The previous chapter explored how citizens act up and into this assemblage through activist organisations and everyday forms of citizen practices; this section extends this analysis to explore some of the institutional actors that constrain the capacity of the state and the citizen to negotiate their vitality.

A principal challenge to global health lies in creating sustainable processes that enable medicines to move from pharmaceutical laboratories and factories, across and within the borders of countries, through government funded public health systems into clinics, and into people's bodies. At the first meeting of BRICS Health Ministers, Sidibé affirmed the 'intimately connected' relationship between people's embodied precarity and the role of BRICS in the global AIDS response:

[T]he five BRICS countries are bringing a new voice, a new perspective and new solutions to today's global challenges. It is a voice with incredible economic,

technological and innovative strength behind it, and at the same time, a voice intimately connected to the needs and interests of the developing world... The geopolitical future is being shaped by yourselves and the alliances you are building (Sidibé, 2011).³⁰

As identified by the BRICS ministers of health at this meeting, this entails transforming complex and expensive processes that prohibit the development and distribution of medicines, like ARVs, from reaching people in developing countries. Four principal challenges to the sustainable provision of essential medicines were identified at this meeting, and form the focus of the section below. First, the threat posed by regional and international actors to individual countries' use of TRIPS flexibilities; "[T]hese take the form of bilateral, regional and multilateral trade agreements such as the EU-India Free Trade Agreement, the Anti-Counterfeiting Trade Agreement (ACTA), the Trans Pacific Partnership Agreement (TPPA) and the Substantive Patent Law Treaty (SPLT)." I discuss, in particular, the potential implications of the EU-India Free-Trade Agreement (FTA) on access to affordable ARVs below. The second, third and fourth challenges relate to the pressure placed on national countries to amend the legislative infrastructure governing the development, importation and exportation of biomedical technologies. This includes the push for countries to amend their intellectual property rights legislation to include TRIPS plus provisions, like Patent Term Extension and Data Exclusivity.

Sidibé argues that universal access to essential medicines will not be possible without the leadership of BRICS member states:

BRICS are faced with unique opportunities to accelerate access to medicines. It is clear that if generic medicines are, for any reason, made unavailable, millions of people will die. The world is looking to the BRICS, who are spearheading a shift in norms, leading the world to accept that access to affordable medicines is a moral obligation—but more than that, a fundamental element of the right to health. It is the BRICS that hold the political and economic clout to defend health against influences that restrict access to generic medicines (Sidibé, 2011).

The world has, and does, look to BRICS countries to ensure and accelerate access to medicines; the history of India and Brazil, in particular, for challenging restrictive international provisions, makes BRICS a powerful actor in the network that enables ARVs to move from the laboratory, over borders and into people's bodies. This history also places pressure on these countries to

³⁰

http://www.unaids.org/en/media/unaids/contentassets/documents/speech/2011/20110711_SP_BRICS-health-ministers_en.pdf; accessed April 2013.

balance neoliberal reforms with democratically established rights to life and health, due to their government's express commitment to rapid economic growth as emerging economic powers. This, in turn, increases the appeal for governments to bow to international pressure in order to secure free-trade agreements, such as the one currently under negotiation with the EU and India.

India's ability to reverse engineer active ingredients has earned it the title of 'Pharmacy of the Developing World', and it is through competition stemming from Indian generics that the cost of first-line ARVs has dropped from more than \$10, 000 per person per year in 2000 to approximately \$150 per person per year in 2012.³¹ By producing low cost medicines through reverse engineering, India has become the largest supplier of antiretroviral medicines to low- and middle-income countries, providing 80% of all donor-funded ARVs to low-income countries (Waning, Diedrichsen and Moon, 2010). The technological capacity to identify and reverse engineer active ingredients relates to the national government's legislative infrastructure that has historically protected its domestic pharmaceutical market, and which has very recently been challenged by the WTO and the European Union. India's government actively encouraged the growth of the domestic pharmaceutical industry from the 1960s, as legislated with the Patent Act in 1970 (which removed composition, but not process, patents from food and drugs). The absence of patent protection in India deterred international companies from entering its market, and enabled Indian companies to carve a niche in the national and international market through its expertise in reverse-engineering. Significantly, India's production of generic AIDS medicines has – through competition – driven down the price of brand name medicines (Bor, 2007; Waning *et al.*, 2010; Jayaraman, 2013; Wouters, Goddeeris, Natens and Ciortuz, 2013).

In the graph developed by MSF below we see that generic competition from companies in Brazil and India pushed down the cost of a first line ARV combination (stavudine, lamivudine and nevirapine) from \$10, 439 per patient per year in May 2000 to \$295 per patient per year in October 2001.

³¹ <http://www.msfastaccess.org>; accessed April 2013.

Sample AIDS triple-combination: lowest world prices per patient per year
(stavudine (d4T) + lamivudine (3TC) + nevirapine)

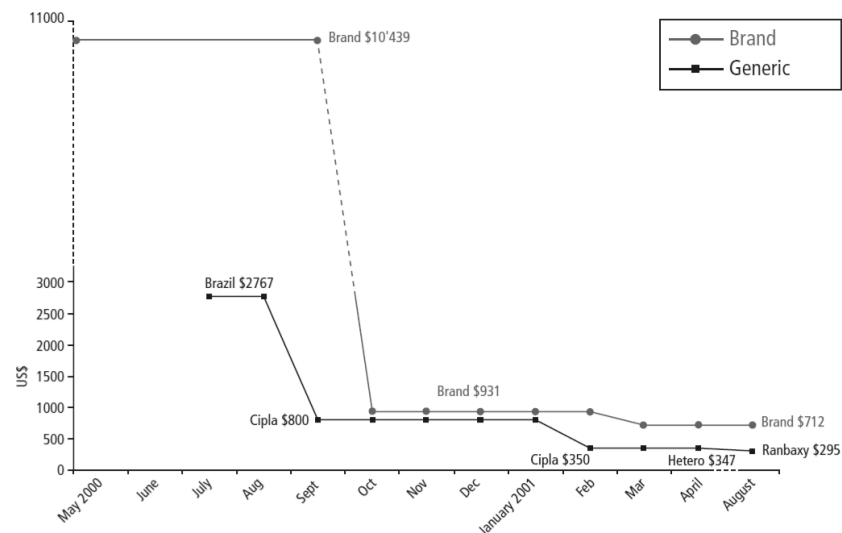


Figure 9.1. The Effects of Generic Competition (Source: MSF, 2001)

The most significant change to India's Patent Act occurred in 2005, when legislation took effect that compelled India to comply with the WTO's TRIPS agreement. This agreement, established in January 1995, includes a set of standards of intellectual property that member states are required to uphold in their law. Under this legislation, India – like Brazil and South Africa – agreed to observe patent protection (on process and composition) for a period of 20 years. This applied to all new patents, and any other patents that had been filed after January 1995. Unless ARV producing countries like India, Brazil and South Africa make use of TRIPS flexibilities, they are unable to import or export these medicines at a reasonable price.

Both India and Brazil have made use of TRIPS flexibilities in order to produce ARVs, but at different points in relation to South Africa's history. Brazil signed onto TRIPS in 1996, almost a decade before India. Like India (although on a smaller scale) and South Africa, Brazil has a domestic pharmaceutical industry and in 2000 it started producing generic ARVs.³² Currently, the Brazilian government purchases 40% of ARVs used in its treatment program from its domestic pharmaceutical industry (Nunn *et al.*, 2009). Brazil's capacity to provide ARVs was facilitated through its domestic production of some AIDS medicines alongside its active negotiation of the global assemblage, including pharmaceutical companies and the WTO (Ford, Wilson, Chaves, Lotrowska and Kijtiwatchakul, 2007; Flynn, 2008; Nunn *et al.*, 2009). Okie notes the effect of these negotiations on reducing the cost of providing ARVs in Brazil:

³² <http://www.who.int/bulletin/volumes/84/5/news10506/en/index.html>; accessed April 2013.

Relying chiefly on domestic generic AIDS drugs and negotiating discounts for drugs that were to be imported have helped the government to steadily reduce its average annual cost for antiretroviral therapy, from \$6,240 per patient in 1997 to \$1,336 in 2004 (Okie, 2006b: n.p.).

Domestic production of ARVs in Brazil has been possible for those ARVs that were patented before 1996, when Brazil signed the TRIPS agreement (as they can be legally produced as generics), and by 2006, 8 of 16 AIDS medicines available in Brazil's public health sector were produced domestically. However, by 2005, the cost of providing ARVs rose to \$2500, "reflecting growing drug resistance and the resultant need for newer and costlier medicines. Imports now account for 80 percent of government expenditures on antiretroviral agents" (Okie, 2006b: n.p.).

Brazil's government was subject to the same international framework governing AIDS medicines as South Africa, but negotiated this framework very differently through its national legislature and use of the international provisions, specifically TRIPS flexibilities that were introduced at the WTO meeting in Doha, 2001. At this meeting, WTO members signed a declaration stating that the TRIPS agreement should be interpreted and implemented by member countries "in a manner supportive of WTO members' right to protect public health, and in particular, to promote access to medicines for all". Specifically, Paragraphs 4 to 6 of the Doha Declaration recognise the right of governments to grant compulsory licenses. Further, it accords members the right to determine what constitutes a national emergency,

or other circumstances of extreme urgency, it being understood that public health crises, including those relating to HIV/AIDS, tuberculosis, malaria and other epidemics, can represent a national emergency or other circumstances of extreme urgency (Doha Declaration, 2001).

The landscape of available AIDS therapies is constantly shifting as new active ingredients are developed that have fewer side effects and are better able to challenge the similarly dynamic virus as it changes shape and becomes resistant to the historical armoury of ARVs. As Okie (2006) notes above, the Brazilian government was compelled by activists to introduce these newer technologies as HIV-positive people developed resistance to the older ARVs. Prior to 2007, one of Brazil's main strategies for accessing medicines (that were not produced domestically) at an affordable price was through threatening to invoke compulsory licenses. This approach had largely worked, and pharmaceutical companies made their medicines available to Brazil's government at significantly reduced prices. However, in May 2007

President Lula da Silva announced that Brazil would follow Thailand's suit and issue a compulsory license to import a lower cost version of efavirenz, patented by Merck. The government estimated that this decision would save the country \$240 million by 2012 (when the Merck's patent expires) (Nunn *et al.*, 2009; Nunn *et al.*, 2012).

The Brazilian government challenged criticisms by business experts and pharmaceutical companies by asserting their decision as one grounded in its democratic constitution, thus legitimising its decision to foreground the lives of HIV-positive citizens over the profits of pharmaceutical companies.³³ For example, a publicity poster jointly issued by the Ministry of Health and civil society organisations, stated, "Local manufacturing of many of the drugs used in the anti-AIDS cocktail permits Brazil to continue to control the spread of AIDS. The drugs industry sees this as an act of war. We see it as an act of life" (Celentano and Beyrer, 2008: 142). While this biopolitical discourse positively and directly positions the vitality of citizens as a function of the 'activist state', it may also strategically obscure other equally radical and less life-affirming biopolitical dynamics. It is worth noting, briefly, that the choice of language in this poster, and in government leaders' description of Brazil's response to HIV, eclipses more complex dynamics, as Biehl (2004, 2006) observes in his ethnographic research, and as I discuss in the section above.

South Africa's capacity and will to negotiate with the international actors that influence the development and distribution of new AIDS therapies has been significantly different from Brazil's. This is not, as we see with countries like Brazil and India, simply a matter of South Africa being forced to capitulate to oppressive capital-driven pharmaceutical companies or the WTO's neoliberal agenda, for example. I suggest below that, at this point in South Africa's political life, it is predominantly a consequence of South Africa's failure to amend its patent legislation. I discuss this legislation briefly below, and contrast it with other regional actors in BRICS as they negotiate the global assemblage governing AIDS therapies in significantly different ways.

In South Africa, in 1997, the newly democratic government indicated its commitment to providing medicines to citizens by introducing The Medicines and Related Substances Control Amendment Act. This allowed the state to substitute brand-name medicines with generics

³³ The US-Brazil Business Council described the move as, "A major step backward for the country's development. Brazil is working to attract investment in innovative industries that rely on intellectual property, and this move will likely cause investments to go elsewhere" (Financial Times, 4 May 2007).

once a patent had expired. This move by the government, one that actively sought to make provisions for providing critical medicines to citizens, was viewed as a threat by the international pharmaceutical community and in 2001, the Pharmaceutical Manufacturers' Association (PMA), including 40 multinational drug companies, took the South African government to court. In one of the few times in South Africa's AIDS activist history, TAC joined the government and successfully challenged the PMA (TAC, 2010). This victory had global implications not only because it compelled pharmaceutical companies to revise the way ARVs were priced (in order to remain competitive with cheaper generic medicines), but it also built momentum for the positive changes to TRIPS legislation marked by the Doha Declaration in November that same year (Nattrass, 2007). The Doha Declaration clarified the rights of member states to use TRIPS flexibilities (discussed below) to protect the health of their citizens.

During my fieldwork, another barrier to accessing ARVs had become the major focus of the AIDS activists with whom I worked. This struggle related to a much older law: the Patents Act 57, passed in 1978. South Africa's sluggish response to changing this law and to incorporating the flexibilities provided through TRIPS has implications for the amount of money spent on AIDS therapies in South Africa, and therefore on the kinds of medicines that are offered through the public sector to HIV-positive people. For this reason, South Africa's patent legislation was the focus of the final Equal Treatment publication (Issue 41) that I worked on during my fieldwork. The title, "Fix the Laws – Save Our Lives", calls attention to the relationship between South Africa's juridical infrastructure and people's lives, again highlighting the biopolitical relationship between the government and its citizens but, importantly, drawing attention to a network of global actors – including countries like Brazil, Thailand, India – that impinge on 'our lives' as South African citizens.

I wrote an article with Nondumiso Hlwele and Nobuhle Qabazi in this issue, and in it we discussed the implications of international regulations for access to new medicines on HIV-positive people's embodied experiences of side effects from old but more affordable medicines (highlighting the value of new AIDS therapies and the importance of compulsory licenses and generic production). Just as TAC had used the constitution, particularly Section 27, in order to support its cases against the government prior to the ARV roll-out, it again referred to this section to support its calls for juridical reform and threatened legal action should "the state fail to meet its constitutional obligations in this regard" (TAC, 2011: 3). The second paragraph of Section 27 stipulates that, "The state must take reasonable legislative and other

measures, within its available resources, to achieve the progressive realisation of each of these rights.” TAC argued that, “One such reasonable legislative measure that the state must take urgently is to change South Africa’s Patents Act so as to ensure access to affordable medicines.” (TAC, 2011: 3).

South Africa grants patents for new uses and formulations of existing medicines; this is not required by international law and is an effect of the national government’s failure to update its patent legislation. Compared to Brazil and India, South Africa grants 50 times as many pharmaceutical patents per year, and therefore, some essential medicines are priced out of reach. In a letter dated 26 February 2013, TAC and MSF called on South Africa’s Minister of Trade and Industry to amend its patent legislation, saying,

The South African government has a constitutional obligation to take all reasonable legislative measures to ensure the progressive realisation of the right to health. Minister Davies will be aware that international trade rules provide South Africa with a number of legal flexibilities that have yet to be written into our national law. The failure to implement such law reform is inexplicable in a country that faces the tremendous health burden that we do in South Africa. It’s therefore high time to change South Africa’s intellectual property laws for the better and to increase universal access to healthcare and safeguard the interests of public health.³⁴

This statement was released as South Africa hosted the Fifth BRICS Summit, with MSF and TAC urging, “[T]he DTI [Department of Trade and Industry] to ensure the timely release of this policy, [insisting] that the policy uphold South Africa’s commitment to join the ranks of BRICS countries protecting public health through their laws and actions.”³⁵ This concern has not only been raised by activists, but has also been acknowledged as a concern by the government. In October 2012, MacDonald Netshitenzhe, Chief Director of Policy and Legislation at the Department of Trade and Industry (DTI) said South Africa had ‘unworkable’ law for issuing compulsory licenses. The DTI had, in October 2012, committed to submitting a new draft policy on Intellectual Property by early February 2013, but had not done so at the time of writing.

Like South Africa, India has signed onto TRIPS but it follows Brazil’s suit (having signed onto TRIPS almost a decade later) in making use of its flexibilities thus enabling India to continue

³⁴ <http://www.msf.org.za/publication/africa-ip-forum-patent-law-reform-long-overdue>; accessed April 2013.

³⁵ http://www.health-e.org.za/news/article.php?uid=20034119&utm_source=Infoblast+Mailer&utm_medium=email&utm_campaign=Health-e+News+Alerts+28+March+2012&utm_term; accessed April 2013.

producing affordable ARVs while not contravening international regulations. I look at three provisions briefly here to highlight the policy implications of South Africa's restrictive legislative framework in relation to these other BRICS countries. The first provision relates to the conditions under which patents are issued. According to TRIPS, a patentable product must demonstrate novelty, be an 'inventive step' and be capable of 'industrial applicability'. Indian law, in contrast with South Africa, explicitly prohibits patents on new uses and new formulations of existing medicines because they do not meet the required standards of 'novelty'. This month, April 2013, India's Supreme Court delivered a landmark judgement that rejected Novartis's 1998 Indian patent application for a beta-crystalline form of a drug called Gleevac that is used to treat chronic myeloid leukaemia (Chatterjee, 2013; Chaudhuri, 2013; Jayaraman, 2013; Ragavan, 2013). In countries where Novartis has obtained a patent for Gleevac, the drug is sold for \$2 600 per patient per month; in India, the generic version of this drug is sold for less than \$200 per patient per month.³⁶ The implications of this case for countries like South Africa highlight the extent to which national actors, like India and Brazil, become implicated in the lives of citizens beyond their own borders. Leena Menghaney, manager of MSF's Access Campaign in India, encapsulates the biopolitical relationship between individuals' embodied precarity and the global assemblage that governs biomedical development and distribution: "The threat to the developing world is real –millions of people rely on affordable drugs from India. If patents are granted more easily in India, patients across the world will see their supply of life-saving drugs dry up."³⁷ Commenting on the Novartis case, Daygan Eager, Researcher with Section27 similarly emphasises the extent to which people's embodied precarity is networked into these complex processes that set precedents for other countries, like South Africa, and their citizens:

[Section]3d [of India's patent law] has been important in blocking patents on fixed-dose combinations and paediatric versions of drugs in India. Because South African law does not have a version of 3d and allows for new patents on old medicines, FDCs and paediatric versions of medicines, which are crucial to the battle against HIV and TB, can be patented here (Eager, 2013).³⁸

The second provision relates to compulsory licenses and parallel imports. TRIPS flexibilities accord countries the right to issue compulsory licenses that allow them to manufacture and/or import generic medicines under patent if these medicines are deemed 'essential'. Countries

³⁶ <http://www.health-e.org.za/news/article.php?uid=20034131>; accessed March 2013.

³⁷ <http://www.msf.org.za/msf-publications/global-health-activists-gather-cape-town-rallying-against-novartis%E2%80%99-attack-on>; accessed March 2013.

³⁸ <http://www.msf.org.za/msf-publications/global-health-activists-gather-cape-town-rallying-against-novartis%E2%80%99-attack-on>; accessed March 2013.

are allowed to issue CLs to export medicines to other countries that are unable to produce or procure these medicines at affordable prices. Provisions around parallel importation also enable countries to import patented medicines if they are sold for more affordable prices in other countries compared to those sold locally. India's patent law provides for any interested party to apply for a compulsory licence; and the law enables Indian companies to manufacture medicines for exportation to countries that do not have sufficient manufacturing capacity. South Africa allows for CLs to prevent patent abuse, but does not explicitly allow for CLs as a way to protect public health, and it also does not clearly permit CLs for export. To date, South Africa has never issued a CL, despite being one of the largest purchasers of AIDS and TB medicines in the world. The implications of failing to issue CLs are tied up in the financial cost of producing or importing brand-name medicines instead of cheaper generics. Simply put, more drugs can be made available to more people when they are made to be cost-effective by using these legal provisions. For example, in February 2013, a CL on a cancer drug, sorafenib, was upheld in India, making it available for 97% less than the brand-name product (Menghaney, 2010; Rathod, 2011). In South Africa, where no generic versions are available, because of the patent law, patients pay R203.50 per 200mg tablet for a drug that costs R8.55 in India. The cost-effectiveness of CLs for ARVs is also evident in countries like Brazil where, as discussed above, it issued a CL on efavirenz in 2007, enabling the government to switch to a generic form.

Third, data exclusivity, which delays the entry of generic medicines onto the market, is not required under TRIPS flexibilities. Indian legislation rejects data exclusivity, but this is currently a point of negotiation between India and the European Union (Modwel and Singh, 2012; Wouters *et al.*, 2013). The effect of enforcing data exclusivity has, for example, increased the cost of medicines in Jordan by 20% (between 2001 and 2007) following an FTA with the EU for which data exclusivity was a condition. South Africa's law does not explicitly reject data exclusivity, which could make it vulnerable to pressure from international trade agreements, such as the one between Jordan and the EU (Malpani, 2007), and the FTA currently taking under discussion with India. The TRIPS agreement, which established a 20-year lifetime for patents (on both pharmaceutical products and processes), was later reinforced by TRIPS-plus in order to lengthen IP rights and provide for stronger enforcement measures. These policies extend international law as defined by the TRIPS agreement, and are not strictly enforceable. However, they can and are increasingly enforced by the EU and the US through FTAs and Economic Partnership Agreements (EPAs). Therefore, although the above flexibilities should be integrated into South Africa's legislation, the extent to which these provisions may – in the

future – be undermined by international actors, like the EU, is still unclear. The European Union, for example, has been in discussion with India to adopt TRIPS-plus measures (Khorana and Garcia, 2013). In addition to enforcing a ten-year period of data exclusivity, the FTA proposes stringent enforcement measures. Thus, the extent to which international actors are networked into the state's capacity to provide and export medicines is illustrated by the relationship between the EU and India; further, the porosity of borders is evident too, if we trace the implications of the FTA on the movement of medicines between India and recipient countries.

Enforcement measures in the proposed EU-India FTA could increase the risk of generics being blocked and seized at international borders. This precedent was heralded in 2008, when generic medicines from India were seized as they passed through Europe's border, because European pharmaceutical companies had claimed that they infringed upon their patents (Waning *et al.*, 2010). As argued above, the extent to which global and regional actors become networked with national governments highlights the limits of Foucault's biopower in which the vitality of the state is drawn into a relationship with the vitality of populations and individuals. This is propelled by the nature of the free market and is evident as pharmaceutical companies slip out of countries and into the transnational space between them. The India-EU FTA could, for example, include an investment chapter that would make provision for companies to sue governments; further, these companies could conduct proceedings out of the public's view (in national courts) through secretive forums. Vocal opposition from activists around the world have placed sufficient pressure on the EU-India negotiations to remove data exclusivity from the draft agreement, also indicating the role of individuals and groups in acting 'up' and through these global assemblages.

TAC and MSF, as actors in this assemblage, have, since their press conference in November 2011 (timed to coincide with the publication of the Equal Treatment issue on patents), been advocating for the South African government to change its patent legislation in order to make use of the health flexibilities contained in the TRIPS agreement. These changes would enable the government to issue a CL for third line medicines – medicines that are becoming increasingly important for people who are developing, or who may in the future develop, resistance to their second line regimens.

8.4. Conclusion

The pandemic is savagely cosmopolitan, making blatant the existence of dynamic, translocal intimacies across received lines of segregation, difference, and propriety. But it has also revived old specters, marking out pathologized publics and crystallizing latent contradictions and anxieties. And in so doing, it has exacerbated existing economic and moral divides on an ever more planetary scale. Coming as it did at the time of a radical restructuring of the axes of a bi-polar world, and of the liberal-democratic nation-state and the workings of capitalism itself, the disease served as both a sign and a vector of a global order-in-formation – and with it, a new sense of the nature and possibilities of the political (Comaroff, 2007: 198).

South Africa's struggle for ARVs was well known among the people and organisations I engaged with in Brazil; partly because it had been covered in the international media and also because TAC and the AIDS Law Project had been working with Brazil's activist networks (Mauchline, 2008). Looking to South Africa, the activists I came to know in Brazil used South Africa as an example of the power of activist coalitions, spanning countries around the world, to effect national and global change. Just as I was cautioned against constructing Brazil as the 'activist state', my fieldwork identified a number of constraints under which South Africa has, and continues to, negotiate international regulations in ways that belie easy categories of the government as having 'denied' or 'enabled' the life of its HIV-positive citizens. It may, therefore, be more accurate to conceive of South Africa's governance structures as networked across scale. Formal government structures are tiered across three spaces: local; provincial; and national. However, this thesis has shown that governance structures are also networked into people's bodies, as they embody renewed life and emergent struggles linked to the biomedicines provided through the public health system. Further, as this chapter argues, these governance structures are networked out into regional and international spaces as South Africa's capacity to procure and provide these essential AIDS medicines are contingent on a network of global actors, including BRICS, the EU and the WTO.

This chapter explored the relationship between the governance of biomedical technology (by actors) and the technologies of governance (through legislature) across a network of actors, affecting the movement of technologies over borders and into bodies. By exploring this relationship of actors across a global assemblage, it highlighted the porosity of bodies, of individuals but also of regional and international coalitions. I propose that there are two

aspects of the biopolitical assemblage that governs biomedical technology: the first relates to substance, the second to actors. The national and international legislative infrastructure governing the development and trade of biomedical technology is extremely complex, and it is not the focus of my thesis. In this chapter I focussed on one substantive aspect – patent laws governing the development and distribution of AIDS medicines – because it was, of all aspects of the global governance of medicines, the most salient concern among the people I worked with. Laws concerning patents and generics all centre back on the active ingredient; when the patent for an active ingredient expires, or when a compulsory license is issued, it is possible to create generic forms of this active ingredient and to sell the medicine for a much cheaper price than their patented counterpart. There are direct, embodied, ramifications of the national and international legislature governing global and national access to AIDS biomedicines.

For, returning to Miriam in the first chapter, we see that the horizon of her life is conditional on her body's ability to work with ARVs in order to continue to outwit HIV's mutations. Her body's ability to 'tame' HIV, as discussed with relation to the new generation struggles, is not only Miriam's individual responsibility, but also relates to her ability to negotiate the use of condoms in her sexual relationship with Samkelo. Part of the reason Miriam is able to negotiate the conditions of her sexual relationship is because she maintains an independent household, and works to secure her own income in extremely difficult working conditions in *uYaphi*. These broader socio-economic conditions are biopolitical, as they draw the state into focus in its historic abuse of power, through apartheid, in creating deeply oppressive structures of governance that systematically disenfranchised the majority of South Africa's population. These factors intersect, and create conditions of precarity for Miriam: Miriam was threatened by her brother because he was unable to secure his own income and, in a drunken state, said he would demolish her home if she did not give him money. In order to protect herself and her child, she was compelled to move into Samkelo's home; and here, she felt unable to insist on using a condom, thus risking the possibility of contracting new viral strains and developing resistance to her ARVs. If South Africa does not change its patent legislation, and if the EU succeeds in forcing India to adhere to the TRIPS-plus regulations, Miriam will have no further option for securing her life on ARVs when she develops resistance to her second line medicines. Quite simply: in 2002 Merck registered a patent on raltegravir, a third line medicine that would likely extend Miriam's life after developing resistance to second line treatment. Under TRIPS, Merck is the only company that can make or sell raltegravir's active ingredient until 2022 (Opar, 2007; van Roey, von Schoen-Angerer, Ford and Calmy, 2008). It is

currently sold for R2, 000 per patient per month in South Africa's private sector.³⁹ Unless South Africa amends its patent act, it will not be able to issue a compulsory license to other drug companies to procure raltegravir in a generic form, should Merck refuse to grant a voluntary license on this patent.

The second point relates to the actors in this assemblage. ARVs, as an actant, draws in a network of actors that spans South Africa, Brazil and India's legislative infrastructures, and their relationship with regional bodies including BRICS and the European Union, and with international bodies like the World Trade Organisation. I engaged with this set of actors because they were most salient in my fieldwork, and they were perceived to most significantly impinge on people's embodied experience of particular kinds of medicines. The women with whom I worked in South Africa are either on first or second line ARVs, and for the moment, these actants are effectively intra-acting with HIV to stop the virus from multiplying in their bodies. However, the emergence of new generation struggles linked to AIDS biomedicines prompts a fresh appraisal of the biopolitical relationship between citizens and the state: as viruses continue to move along pathways of precarity, they become – over time and through contact with different viral strains – adept at mutating to resist older AIDS biomedicines. This new horizon of biopolitical precarity will, over time, become more salient as people develop resistance to second line ARVs and, without access to third line biomedicines, face death because they cannot afford to purchase life and buy these essential drugs through the private sector. Therefore, just as the historic struggle for ARVs in South Africa drew in a transnational network of actors to enable, and then compel, the government to provide these essential medicines, this chapter demonstrated how this new horizon of biopolitical precarity similarly draws attention to the value of understanding how this dynamic global assemblage has current implications for people's embodied vitality.

The diverse set of actors that shaped the evolution of South Africa and Brazil's response to HIV highlights the extent to which individuals, activist networks and policy makers intra-act to co-construct health policy through these networks of governance. This challenges binaries like citizen/state and unidirectional assumptions of biopower. James Ferguson (2006) similarly questions the usefulness of concepts like 'civil' and 'local', suggesting that international NGOs (like MSF) have, in some African countries, come to take a 'state-like' shape. He writes, "The globalization of politics is not a one-way street. If relations of rule and systems of exploitation have become transnational, so have forms of resistance" (2006: 109). Of pertinence here, is

³⁹ <http://www.fixthepatentlaws.org>; accessed June 2013.

that Ferguson similarly suggests that the globalisation of politics requires us to rethink the problematic construction of biopower as unidirectional, acting 'down' onto the bodies of individuals and populations.

However, as I have argued across this thesis and as I conclude in the following chapter, the extent to which life is contingent on international actors runs alongside another narrative: people do not simply embody precarity because they are acted 'on' by actants, like HIV, and actors, like national governments or international organisations that regulate a country, and therefore a citizen's, access to life-sustaining medicines. As the accounts above illustrate, and as I have explored throughout this thesis, people in both Brazil and South Africa have actively engaged with this global assemblage in order to bring ARVs out of laboratories and factories in places like US and India, into their country, into their public health systems, and into their bodies. Reflecting on Comaroff's (2007) observation above, it is perhaps, then, the people within this global assemblage, and not the virus, that have generated "a new sense of the nature and possibilities of the political" (2007: 198).

9. Biopolitical Precarity in the Permeable Body

President Zuma's face smiled down from a large billboard, impressing his vision for South Africa onto throngs of jetlagged people as we navigated our bodies and luggage trolleys out of Cape Town's International Airport. His vision reflected the Government's key priorities, many of which, as discussed in the previous chapters, are shared by HIV-positive men and women living in Khayelitsha's corrugated iron and cardboard shacks; homes I flew over as my plane came in to land in February 2013, 18 months after completing my fieldwork. The billboard emphasised the government's commitment to creating decent jobs, education, health, fighting crime, and rural development. I manoeuvred my luggage under the billboard, past a desk welcoming visitors to the 5th BRICS Summit, and into the car.

Pondering Zuma's vision, I assumed that the billboard I drove under when leaving the airport – which read 'We Promise. We Deliver' set against a photograph of tens of newly built homes – was also a part of the Government's publicity machine. I was wrong. Anglo American's name ran along the bottom.

With Khayelitsha behind me and Table Mountain in front of me, I drove past the green mosque that marked the turn-off to Nyanga - Khayelitsha's neighboring township and my fieldsite in 2003. In the course of my ethnography with Luvuyolwethu, an HIV home-based care organization, I came to know Nyanga's streets as I walked from one home to another with the carers during their 'rounds'. This is how I met Peggy. She lived with her 22-year-old son, Zithulele, and her 25-year-old daughter, Patricia. When I started my fieldwork, Patricia was still able to sit up in the bed that Luvuyolwethu had set up in the sitting area of Peggy's home. Without ARVs, HIV had become AIDS and Patricia had become immobile. We did not realise – or perhaps articulate – that when we moved Patricia from her bed to lie down in the back seat of my car, eventually to lie down in Groote Schuur hospital, that she would not come back home. We went to visit Patricia a few days later: on the cusp of death, she had been heavily sedated with morphine. After driving in silence most of the way back home, Peggy pulled her jersey more tightly around her body and said, "I fought in the streets for this government. Now the holes in my roof are just bigger and they are not giving me medicine for my daughter." Patricia died three days later, just a month before the government was forced by cabinet to initiate the ARV roll-out.

Peggy's dismay that the government she had fought to give life to had not fought harder to give life to her daughter was echoed by a large loud public surge of anger across the country. As TAC launched a civil disobedience campaign demanding a public sector ARV programme, academics and activists alike looked to companies like Anglo American and to countries like Brazil as models for delivering ARVs to people, like Patricia, whose lives were precariously woven into the life of South Africa's decade-old government.⁴⁰ By providing medicines to their employees in the absence of a public-sector roll-out, Anglo American highlighted the state's failure to deliver essential medicines to its citizens (George, 2006; Bolton, 2008; Rajak, 2010). By navigating complex international regulations on pharmaceutical production and procurement in order to provide ARVs in its public health system, Brazil highlighted the South African government's capacity and constitutional responsibility to deliver these medicines (Nunn et al., 2009; Nunn et al., 2012).

At that time, in 2003, the presence of the post-apartheid state in people's lives was felt through its absence, embodied in death, evident in the blossoming of wooden crosses on graves carefully dug to run as closely as possible alongside each other. In the course of my fieldwork that year, the graves had pushed out and against the feeble fence that lined N1 – the main road that ran like Nyanga's spine between this space of death and homes of Luvuyolwethu's clients as they navigated their precarious lives. On a bitterly cold winter's day in July 2003, Peggy's family and I clustered around the parcel of earth that had been designated for Patricia's grave as her minister led the funeral. When we returned to Peggy's home after the ceremony we all washed our hands in one of the three buckets that had been placed on the street outside her front yard. Peggy explained to me that by washing our hands after Patricia's burial we signified to the ancestors that we had distanced ourselves from death and looked, instead, towards life.

In this pre-ARV era, HIV became AIDS became death so rapidly that the forward slash between HIV/AIDS made sense. In 2013, it no longer does. AIDS biomedicines have pried open the space between HIV and AIDS. Now, as I argued across this thesis and conclude in this chapter, this opening out of life brings to light a set of complex challenges around the biopolitics of AIDS biomedicines and the socio-economic conditions in which life on ARVs is lived. These new generation struggles call into focus an assemblage of actants and actors that, together, are networked into women's embodied precarity. This thesis argued that while a longer life with

⁴⁰ <http://www.tac.org.za/Documents/CivilDisobedience/briefingdocument.htm>; accessed April 2013.

HIV is possible through ‘technologies of life’ like ARVs, for the women I worked with it is still a precarious life that, everyday, pushes out and against the possibility of death.

The first section of this chapter returns to the starting point of this thesis; while it is not an ethnography that starts from the point of bare minimalisms, it is also not an ethnography of hope. It lies somewhere in between, and the first section notes the ethical implications of this location in a ‘muddier middle’. The second section outlines the main findings and conclusions from the thesis, and the final section reflects on the conceptual and methodological framework and explores areas for further development.

9.1. Between Hope and Dystopia: Precarious Life in the Muddier Middle

In 1971 Albert Hirschman challenged social scientists to disrupt their assumptions about the world, to relinquish their attempts to fit complex social, economic and political transformation into paradigms that had become so familiar they stopped being analytically helpful. Instead, looking particularly to South American countries, he challenged us to engage the unexpected. The ethical implication of this challenge is captured by Joao Biehl’s (2007) description of the right to a nonprojected future, where thinking beyond what we perceive to be possible is not only intellectually important but ethically critical:

At stake is helping to defend the right to a nonprojected future as one of the truly inalienable rights of every person and nation; and to set the state for conceptions of change to which the inventiveness of history and a passion for the possible are admitted as vital actors (2007: 3).

In his reflections on Hirschman’s call with respect to his ethnography of precarious life and access to AIDS medicines in Brazil, Biehl (2005) explains that engaging the unexpected is not simply an abstract academic principle, but that it is an ethical task. By thinking beyond the limits of what is perceived to be possible, Biehl argues that we call into focus the biomedical horizon of HIV-positive people’s future; in a nonprojected future, life opens up to unexpected potential – it does not close down towards premature and imminent death without AIDS biomedicines.

When Zama spoke of the skies that fight in the first ethnographic chapter, she reminded us of this ethical task and complicated its application. Her account of these skies took us to the Eastern Cape, and the moment in her life when lightning struck and HIV entered her body; at

this time, too, ARVs were not available in the public sector and the hope for living a long life with HIV was not yet a reality. The absence of ARVs in this particular topology of time-space and memory may account for the layered ways that Zama made sense of her body's weakness, and looked for healing, when she first became seriously ill with HIV, as discussed in Chapter Seven. Zama's account of her rapidly weakening body, at first glance, perhaps offers up a figure of homo sacer (Agamben, 1998a); and the start of Chapter Four may resonate with Thin's description of ethnography that starts from the point of 'sheer minimalism' (2008: 149). For, a reading of the skies that fight may cast Zama as an HIV-positive citizen whose life, and death, is almost wholly tied into the state's failure to provide life-saving biomedicines. However, the chapter moved from Zama's description of the skies that fight, the dystopic starting point in her own political struggle for life linked to medicines, to a time ten years later. At this time, South Africa had the largest ARV roll-out in the world and activists like Zama were looking to a precarious future that, with ARVs, also held hope.

The hip-hop and poetry event Zama took me to, at the end of my fieldwork, also looked to South Africa's history in acknowledging the work of James Matthews, an anti-apartheid poet; but it brought the country's history into the present with a mash-up of hip-hop dancing and beat poetry that spoke to contemporary challenges facing South Africans, like unemployment and gang violence. It was in response to a question by Matthews's grandson that Zama explained that her dreamt future as a much younger woman – from a time before the fighting skies – had become a present reality. She said, "I am an artist. I am my dream."

Zama's account of dreamt hope as reality was entwined with another set of quieter narratives that I learnt to hear more clearly over time. I discussed these layered narratives in relation to the pathways of precarity that brought HIV into the bodies and lives of the women with whom I worked. It was only once I had recognised the importance of looking towards a future of hope, and once I had acknowledged the presence of this future in Zama's life, that – after eight years – we began to have conversations that moved into the muddier space between the 'sheer minimalisms' of structural violence that 'acted down' and the 'hope' offered by ARVs and activism that 'acted on' these structures. This thesis – like my relationship with Zama – shifted across time and is rooted in a muddier middle ground between the hope that lies in imagining future possibility, and the dystopic violence and threat of death that call into focus the present precarity of people's everyday lives in Khayelitsha.

While the ethical task for this ethnography was to look to the horizon of possibility, of a long life where Zama raises her son into adulthood and continues ‘being her dream’, I found that this is not enough. In addition to looking out to the horizon, towards the hope of a nonprojected future, I argued in this thesis that we need to recognise that biopolitical precarity is embodied in the present, and that it is a discursive outcome of an assemblage of actants and actors that coalesce around the governance of technologies. Because this ethnography is situated in a muddier middle ground, I propose an ethics of accountability in which we hold actors at the greatest distance from us in the global arena accountable for the extent to which they are implicated in shaping the very lives of the smallest nonhuman actants, like HIV and AIDS biomedicines, in the most intimate space of our bodies. Further, I propose an ethics of accountability in which we recognise the fraught terrain of agency in this muddier middle ground: while calling actors to account for their implications in women’s embodied precarity, this ethnography has shown that it is critical to gauge calibrations (rather than absolute assertions) of agency in the space between structures that ‘act down’ and agents that ‘act up’. By only focusing only on agency and hope, or only on structures and bare life, we risk eliding the everyday ways that people navigate a vitality that is both precious and precarious.

9.2. An Ethnography of Precarious Life: Findings, Contributions and Conclusions

Technology is not neutral. We’re inside of what we make, and it’s inside of us. We’re living in a world of connections — and it matters which ones get made and unmade (Haraway, 1991: 149).

One of the ways that we can engage the unexpected, according to Latour (1993), is to move away from analytical approaches that ask us to compartmentalise complex networks into, “only science, only economy, only social phenomena, only local news, only sentiment, only sex” (1993: 2). Like Haraway (1991) before him, Latour (1993) calls us to think more carefully about the world of connections in which we live. As far back as 1993, when Latour wrote *We Will Never Be Modern*, HIV had already become a powerful exemplar of the value in tracing the ‘delicate network’ that mixes up “heaven and earth, the global stage and the local scene, the human and the nonhuman” (1993: 2). HIV is indisputably powerful as an actant in its capacity to shift the “geopolitical coordinates within which we think and act” (Comaroff, 2007:

198); and together with the similarly shape-shifting lives of AIDS biomedicines, these actants call for theoretical agility:

We may lack the nerve or imagination to theorize [AIDS] adequately, but it has certainly been theorizing us for quite a while... The threatening mutability of the disease challenges efforts to impose stable categories of recognition and exclusion in an already disrupted late-modern geography (Comaroff, 2007: 198).

I took this observation as a challenge: in developing the concept of biopolitical precarity, and by theorising AIDS through the notion of HIV and ARVs as actants, this thesis articulated the nature, function and implications of a global assemblage as it is woven into people's lives and their embodied precarity. Further, it considered how actants and actors are not only 'acted on', but how they act up and through this assemblage to navigate their vitality. Therefore, each chapter explores in turn how actions by actants (HIV and ARVs) and actors in this assemblage ricochet across the network, moving across the permeable boundaries that connect rather than separate the body of the state and the state of the body within a global arena.

I discuss the main findings and conclusions from the thesis below. The first sub-section outlines the main findings from the chapters, and concludes with a question that this thesis came to ask of the politics of life literature. The subsequent sub-section responds to this question and through this response, it proposes two conceptual contributions drawn from the thesis. Thereafter, as a summary of these two sections, I articulate the five main conclusions that emerge from the thesis as a whole.

9.2.1. Looking Into the Thesis: The Main Findings

This ethnography was configured to trace the political and embodied dimensions of accessing AIDS biomedicine for women living with HIV in Khayelitsha, South Africa. These two research dimensions – the embodied and the political – emerged from my personal and professional background and from South Africa's political history, as outlined in the Introduction. The rationale for the embodied dimension of this research lay in the shifting biomedical landscape where AIDS biomedicines had become internationally available, but were initially blocked from entering South Africa's public health system under the Mbeki-administration; by the time I started this PhD in 2009, these medicines had still not met the 2007 – 2012 policy target of reaching 80% of all those in need of ARVs. The rationale for the political dimension of this research was underpinned by the shifting political landscape. As I commenced my PhD, the

Zuma-administration had recently been elected to power and the historical antagonism between AIDS activists and the government shifted with Zuma's evinced commitment to addressing HIV in South Africa.

The increasing availability of ARVs in South Africa alongside the shift in AIDS activism towards a fuller collaboration with the government, prompted me to understand the challenges that emerged in the wake of the visible struggle for life linked to biomedicine. These challenges, referred to as 'new generation struggles', had a dual character: first, they related to accessing newer biomedical technologies that had fewer side effects, and third line treatments that would enable people to continue living when HIV started to resist second line biomedicines; second, they related to the socio-economic dimensions of precarity, including chronic unemployment and economic insecurity, that women embody as they navigate their lives in Khayelitsha. Therefore, while my research focus built on these shifting biomedical and political landscapes in the decade leading up to my fieldwork in 2010, my ethnography explored their intersection. This thesis, therefore, emerges from and articulates an integrated biopolitical landscape in which the vitality of citizens and the state are porously networked into an assemblage of actors and actants that coalesce around the global governance of AIDS biomedicines. The five ethnographic chapters detailed this assemblage across scale, starting under the skin as HIV and ARVs became animate in women's bodies and lives, and moving out to the national space as women saw and spoke to the state, and to the global arena where national and international legislation governs the extent to which these women are able to access the hope of a long life on ARVs.

Chapters Four and Five introduced HIV and ARVs as nonhuman actants in the assemblage. Together, these chapters engaged with the dimension of my research focus that concerned women's embodied experience of AIDS biomedicine. Looking back in time to the 'skies that fight', Chapter Four traced the vertical, horizontal and diagonal pathways of precarity that the virus travelled to enter the lives and bodies of the women I worked with. In doing so, I argued that these pathways complicate social science readings of the 'gender-HIV' dyad in which Black poor women are constructed as socio-economically and biologically vulnerable. While these three pathways connect to a larger background of studies on socio-economic inequality and HIV transmission in South Africa, we see a further two dynamics that muddy this reading when analysed through the lens of biopolitical precarity. First, this chapter not only explored how HIV entered women's bodies, but it also demonstrated that women actively 'acted on' the implications of HIV in their lives through engaging politically as activists within TAC to bring

AIDS biomedicines into the country and into their bodies. It also demonstrated the myriad, and often fraught, tactics women employed in their sexual relationships to balance their desire for intimacy with their awareness of the embodied risks and sometimes the material benefits of unprotected sex with their partners. Second, in considering these pathways through a biopolitical lens, this chapter proposed that by analytically focusing in on women as vulnerable victims and men as active perpetrators, we place the state on the periphery of our vision and therefore do not hold it accountable for addressing the structures (primarily linked to health, education and employment) that engender biopolitical precarity for both men and women.

When HIV travels along these biopolitical pathways, it enters a new phase of life within the body: here it learns to mimic the DNA structure held in the CD4 cells – the very cells of the body that would have otherwise been responsible for blocking HIV from replicating and enabling a syndrome of illnesses to plague the body. ARVs were originally developed in order to block the life of HIV inside the body; now they are developed, too, to intra-act with particular strains of the virus as it mutates and changes shape in the body over time in this shifting biopolitical landscape. Prior to my fieldwork, I had witnessed a decade-long struggle to bring these critical medicines into South Africa's public health system, and into the frail bodies of people like Patricia who would die because they could not afford to buy a longer life in the private health system. However, as a result of the shifting biopolitical landscape that I describe above, access to ARVs was no longer the primary problem for people living with HIV in urban areas like Khayelitsha. Instead, as discussed in Chapter Five, I observed a set of new struggles that related to the intra-action of HIV and ARVs with and in the body and to the socio-economic context in which people navigated their lives on ARVs.

By drawing AIDS biomedicines into focus as nonhuman actants, Chapter Five introduced the argument that women's embodied experiences of precarity are not only related to HIV (as a problem) or medicines (as a solution to HIV), but to the complex intra-action of these actants within the body; further, it argued that women's everyday struggles to navigate their bodies and their lives in a context of intransigent socio-economic inequality is fundamentally embodied. The dual character of these 'new generation struggles' speaks to recent ethnographies from Tanzania (Marsland, 2012), Brazil (Biehl, 2005), Kenya (Prince, 2012) and South Africa (Le Marcis, 2012) that similarly call attention to the limits of the 'politics of life' literature as it does not pay sufficient attention to contexts in which people live and the forms of inequality that shape their lives and even affect their ability to sustain life on ARVs.

However, as I discuss below, these new generation struggles also present a slightly different argument to this emerging literature.

In Chapters Four and Five I traced the pathways that brought HIV and ARVs ‘to life’ in people’s lives. By integrating an analysis of these pathways with the concept of biopolitical precarity, I proposed a reading of the body as permeable. Chapter Six then traced these pathways as they were recounted through Anamnesis, and as they were located in shifting space-times, which underlined the extent to which topologies of illness and medicine are embodied. I considered the political implications of this argument in Chapters Seven and Eight and, across all five chapters, proposed that there is value in thinking across the boundaries that separate what happens ‘inside’ the body from what happens ‘outside’, also described as the context in which people live. This argument reflects the intersection of the two dimensions of my research – the embodied and the political. Historically, ethnographers have explored this intersection primarily around the politics of life linked to the capacity of the state to ensure that citizens are able to access ‘vital technologies’ like ARVs. Robins (2006), for instance, has described the bare life and the vital politics he observed during his fieldwork, also in Khayelitsha, at the height of the struggle for ARVs. Like Biehl’s ethnography in Brazil (2005, 2007), Nguyen’s analysis of therapeutic citizenship in Burkina Faso similarly draws attention to the transnational networks of activist organisations, health care workers, national governments and international trade laws through which HIV-positive citizens mobilise around their right to access ARVs (2005, 2010). While I acknowledge the biopolitics implicit in access to ARVs, the timing of my ethnography and the corresponding findings of my fieldwork suggested that there are emerging forms of biopolitical precarity that move away from situating ARVs as the technofix to the problem of HIV. In looking at HIV and ARVs as actants in a global assemblage, we see that they have multiple and mutable effects on people’s bodies and within people’s social, sexual, political and economic relationships.

Looking ‘inside’ the body, this ethnography found that ARVs are embodied in many different ways, and that this embodiment was not uniformly positive. Sindiswa, for instance, described how older biomedicines like d4T were embodied as lipodystrophy, whereas Yvonne found that nevirapine had placed strain on her liver. The accounts of side effects, viral resistance and treatment fatigue are not a totalising view of the effect of ARVs on the bodies and lives of the people I worked with; but they were an important finding of my ethnography as these narratives surfaced frequently as complaints during clinic visits, or in conversations with friends while standing in the queue for ARVs. I saw, too, that for people like Nondumiso, the

embodiment of HIV was not uniformly negative; she explained that HIV had been a resource that had enabled her to travel to countries like Canada, and to engage with international artists who, like her, acknowledged that they lived with a chronic illness but refused to be identified by their illness. As Nondumiso explained, “I live with X, where X could mean anything.”

A tension emerged: by acknowledging that HIV was a present reality in her life, Nondumiso and the other women I worked with had managed to secure a stable income through their social ties into a network of HIV activist organisations and academic programmes in Cape Town. However, their employment was also tied into a global terrain of AIDS funding and into the Global Fund in particular; Chapter Five detailed the implications of being networked into these organisations, and precarious funding structures, as Lilian, Yvonne, Zama and Sindiswa had all lost their secure income in the course of our work together or shortly after I had finished my fieldwork. This brings us to the second character of the new generation struggles, which related to the persistent precarity that women experienced ‘outside’ their bodies in their homes, in Khayelitsha’s streets, in uncertain employment as they navigated entrenched socio-economic inequalities and pushed back against the ever-present threat of poverty. The tension around wanting to avoid categorisations like ‘HIV-positive’ whilst accessing resources through their HIV status persisted as the women I worked with struggled with organisations that offered a meager but vital wage for work that was built and sold around assumptions of poor, Black, HIV-positive women as ‘deserving subjects’. Here too, as discussed in Chapter Five, women resisted these categories through everyday tactics – like talking in isiXhosa about the income generation manager in his presence, and frustrating him because he knew that they were discussing him but was powerless to challenge them. This is very much in line with de Certeau’s (1984) description of ‘making do’ in everyday life through these tactics of resistance.

Therefore, as ‘things’ with social lives (Appadurai, 1988), HIV and ARVs intra-acted with each other and with(in) individual bodies in complex ways that disrupt the binary that positions ARVs as the ‘technofix’ to the problem of HIV. Further, we see that these actants themselves are not uniform: specific forms of older biomedical technologies (like d4T) were identified as causing side effects, whereas newer medical technologies (like lamzid) were perceived as more desirable for managing both HIV and possible side effects from ARVs. HIV, too, is not a fixed virus, but has many hundreds of thousands of strains that require scientists to constantly work at generating newer medicines that can outwit the ever-changing virus. Further, HIV was not

only embodied as a problem; it was also strategically mobilised by the women's subversive performance of precarity in order to access economic resources directed to them as the 'deserving poor'. However, this performance, itself, was precarious as the wave of AIDS-specific funding receded, and as organisations appropriated these labels, thus 'exploiting my HIV', in order to propel gross profits through national and international sales of paper mâché bowls made by 'poor, HIV-positive, Black women'.

The timing of my fieldwork may account for the emergence of these new generation struggles linked to the intra-action of HIV and ARVs, and the socio-economic context in which people live. Or it may simply be that these struggles existed all along and I and other researchers had not paid sufficient attention to them at a time when the grey space between 'science' and 'denial', and the urgency of survival, asked for solidarity and agreement that ARVs were unequivocally the solution to HIV. Chapter Six explored this longer-term history through the concept of Anamnesis. In this chapter, we travelled on the N2 highway between the Eastern and Western Cape Province with the women, through their photographs and their illness narratives. These narratives were striking in their shifting construction of 'home' in the Eastern Cape as a place that held both risk and romance; it was, for many of the women I worked with, the place where they had first entered sexual relationships, and so it was also, according to the women's recollections told in this chapter and in Chapter Four, the place where HIV first entered their body. The gendered dynamics of the Eastern Cape were highlighted as particularly risky, described through Anamnesis in relation to male circumcision practices and the expectations of masculinities that were instilled during this initiation. On the other hand, the Eastern Cape was also described in contrast with Khayelitsha as a far safer and healthier place to live; it was, however, the search for medicines in order to sustain their own and their children's lives that brought most of the women to the Western Cape. Within the Western Cape, Khayelitsha in particular represented the hope for a long life as it was the first place that offered ARVs to South Africans in the public health sector. Through Anamnesis, these memories of illness and the search for health were joined with South Africa's shifting spaces and times. It was through their experience of precarious life, linked to shifting space-times in South Africa, that these women joined TAC and engaged with the state and global actors (like pharmaceutical companies) as citizens in calling for access to ARVs that would enable them to live a long life, and that could stop the movement of HIV along vertical pathways into their children's bodies. I described the conjunction of these recollections with space and time as a topology. Further, I suggested that these topologies are embodied and that they point to the ways that actants (like HIV and ARVs) and actors (like activist organizations and government

policies) come to take on life and are configured within an assemblage across scales spanning time and space.

As stated above, in the era preceding my fieldwork, activists and activist organisations like TAC and MSF called for epistemological solidarity that unequivocally foregrounded the efficacy of biomedicine. This activist discourse had social and political implications as it worked to draw people together around their sense of precarity linked to the absence of ARVs in the public health system, and therefore created strong social ties between people based on their shared HIV-status. Now, a decade after ARVs were first introduced in the public sector, South Africa has moved into a muddier middle ground, and the Zuma-led government and activist organisations like TAC have entered a collaborative rather than combative relationship. This political shift in the governance of HIV and its treatment ran alongside two other dynamics that I observed in my fieldwork and that bridge the embodied and political dimensions of my research. First, at an individual level, HIV and ARVs intra-act with each other and with(in) the body in complex ways, across time, that ask us to look more closely at these actants and their social lives. HIV is not a uniform virus; it has many different forms and when it meets another form of the virus, through unprotected sex, it is able to mutate within the body, and through this process, it can learn to resist older forms of ARVs. ARVs too, are not uniform, but unique technologies that have different properties and are also under constant scientific development to more effectively block the life of HIV.

This takes us out to the second dynamic: the global development and distribution of AIDS biomedical technologies. While all chapters consider the ways women conceptualised the biopolitical role of the state in their lives and bodies through the lens of AIDS biomedicines, Chapters Seven and Eight tessellate closely as they point to the porosity of the state and the limited capacity of both individuals and governments to negotiate access to these medicines within a global assemblage. I argued, through these chapters, that although historic readings of biopolitics (see Agamben, 1970; Agamben, 1998a) position citizens and their vitality as a function of the state, AIDS biomedicines confound this reading. Instead, they point to the value of thinking about networked governance that extends beyond the citizen-state dyad to include a range of global actors that permeate the boundaries of this dyad. Because India has asserted, through its own national patent legislation, its right to produce and sell generic medicines, countries like South Africa and Brazil have been in a position to afford to purchase these medicines at a scale that reaches most of its citizens through their public health systems. Now, with South Africa's outdated patent legislation and with the EU-India trade negotiations

currently underway, the South African government might find that it can no longer import these generic AIDS medicines. The final two ethnographic chapters, therefore, traced the connections that weave women's embodied precarity into an assemblage that includes these national governments (South Africa, Brazil and India), regional coalitions (like BRICS and the EU) and global actors (like the WTO). They argued that, together, these national, regional and global actors govern the development and distribution of more effective biomedical technologies that have fewer side effects, like lamzid, and third line AIDS biomedicines, like raltegravir, that offer hope for a longer life when HIV develops resistance to second line treatments.

Given the historical call for epistemological solidarity around the uniform efficacy of AIDS biomedicine in their most general sense, the timing and therefore the findings of this ethnography pose new questions to the politics of life literature. When we acknowledge that HIV and ARVs are differentially embodied, and that the context in which people live is embodied as biopolitical precarity, what happens to the historic social ties built around HIV as a shared illness, and what are the implications of these diffracted socialities for biopolitics and citizenship?

9.2.2. Looking Across the Thesis: Conceptual Contributions and Main Conclusions

This sub-section outlines two responses, and conceptual contributions, to the question this thesis asks of the politics of life literature. The first relates to the nature of diffracted biosocialities and their social and political ramifications; and the second relates to the conceptual integration of the two aspects of this thesis – the embodied and the political – through the concept of biopolitical precarity. Thereafter, it draws together the discussion in this section and outlines five main conclusions.

Contemporary ethnographies on ARV programmes in Tanzania (Marsland, 2012), South Africa (Le Marcis, 2012) and Kenya (Prince, 2012), suggest that Rabinow's (1996) historic framing of biosociality precludes a contextual understanding of people's multiple and shifting subjectivities (Whyte, 2009). For instance, in her research in Kisumu, Prince observes that:

[T]he ways in which people are learning to live with HIV suggests that they are indeed enacting biopolitical frames, but that while these may be disciplining, they also open up opportunities, for revaluing one's life, for creating new social networks, for making a living (Prince, 2012: 548).

Marsland similarly critiques the historic emphasis on the 'bio' in biosociality and suggests that by looking at illness, or at biological predispositions to illness, we fail to see the layered and complex social relationships that people form around multiple struggles for survival that extend beyond access to ARVs. She writes,

Biosociality is laid down along already existing networks of family and neighbors, reinforced by shared practices, such as clinic attendance, and the recognition of symptoms in others that have been experienced in one's own body. These paths were unevenly trodden resulting in some tightly knit groups... Others were not so obviously biosocial: isolated individuals who did not wish to disclose their secret; and looser configurations of friends who did not self-consciously coalesce into 'groups' but sometimes accompanied each other into town on clinic days, or occasionally met each other at home for conversation over cups of tea (2012: 473).

These authors offer a set of ethnographically grounded critiques of the politics of life literature and the absence of serious engagement with inequality by those authors who are, predominantly, based in the global north such as Rose (2005, 2006) and Rabinow (2006). In effect, these new ethnographies de-centre the biology of illness and draw into focus the importance of locating people's lives, including their experiences of illness, in a broader context of chronic poverty. They ask us to consider what we may be missing by focusing solely on social relationships that are formed around illness and its medicines.

This thesis connects, in many respects, to the critiques offered by these authors. As described in Chapter One, the biopolitical struggle for life was strongly tied into the biology of HIV and the necessity of ARVs to stop HIV from replicating in their body and moving into AIDS. It was in joining TAC that all of the women I worked with came to forge biosocial ties with each other; these socialities persist, but as I indicated with respect to the description of the dual character of the new generation struggle, they have also diffracted out from the initial struggle for AIDS biomedicine to incorporate an emergent set of claims around access to newer biomedical technologies. I therefore used the term 'diffracted biosocialities' to denote the emergent and plural nature of forms of biosociality that have fanned out from the initial single focus on HIV and its medicines in South Africa. The dual character of the new generation struggles supports the critique of the politics of life literature outlined above, as it shows that it is not enough to simply look at the social and political relationships that may be formed around HIV and AIDS biomedicines. However, my research suggested two further ways of asking questions of the

politics of life literature; they still engage with the issue of inequality, but propose a different approach to the nature of biosocialities I observed in my fieldwork.

First, the women's accounts of their differentiated experiences of both HIV and ARVs inside their body – historically read as the 'bio' in 'biosociality' theory – indicate that the nature of biosocialities in South Africa is shifting away from a single focus on HIV; now, they have diffracted out to include an emergent set of struggles and corresponding social and political responses to the embodiment of HIV and ARVs over time. As outlined above, the dynamic intra-action of HIV with ARVs has resulted in a set of emergent concerns around viral resistance, side effects and treatment fatigue. The conversations I observed were no longer about the risk of dying without access to ARVs and the resultant political actions through which women asserted their right to life in court rooms and public marches. Instead, these quieter conversations within this network of activists, who had now become friends, were around side effects of older biomedicines like d4T and the importance of sustained social support, through support groups, to manage these side effects. These socialities, forged through the longitudinal concerns raised by both HIV and ARVs, have also precipitated a series of political actions. TAC, for instance, acknowledged that HIV and ARVs were differentially embodied and had started a new political dialogue with the government and with its members – seen in the Equal Treatment issue on side effects and adherence discussed in Chapter Five. This dialogue acknowledged some of the uncertainties linked to ARVs beyond the historic assertions that ARVs were all the same, and that they were unequivocally positive in transforming people's bodies from 'bare life' to full health. By articulating the ambivalent embodiments of biomedicines with each other and in the ways they 'saw' and 'spoke to' the state in their photographs and films, the women with whom I worked called on the government to provide newer medical technologies, including third line treatments and to invest in finding a cure to eradicate HIV altogether. As then discussed in Chapter Eight, these new embodied struggles with medicines have been picked up by TAC in its recent calls on the government to amend its patent legislation.

Second, in addition to the embodied struggles linked to these shifting actants within the body, Chapter Seven described the multiple forms of embodied precarity that bring the 'outside' context in which people live 'inside' their bodies; these emergent claims were communicated as people saw the state each time they left their home in the middle of the night to use the single, often locked and poorly lit, public toilet in their neighbourhood. They were communicated, too, through photographs of live electricity lines that ran through the sand,

under their feet, or over the heads of their children as they played in the garden. By exploring how socio-economic inequalities are embodied, this thesis integrates the political and embodied research dimensions and argues that inequalities that are conceptualised as existing ‘outside’ the body – in electricity lines and darkly lit public toilets – are, like HIV and ARVs, embodied ‘inside’ as forms of biopolitical precarity. Not only are these multiple forms of biopolitical precarity embodied, but like HIV and ARVs in the era before my fieldwork, they have created new social and political ties. Activist organisations, like TAC, and individuals who had historically called on the state to provide ARVs had, with time, started to support (and even start) a plethora of social justice organisations that lobbied the government for better sanitation, an end to sexual and gender-based violence, and equitable education. I therefore refer to these emergent social and political ties, linked to both dimensions of the new generation struggles, as diffracted biosocialities.

With respect to the questions this thesis asks of the politics of life literature, I propose, then, that ‘contextual’ inequalities are fundamentally embodied; and because these inequalities are perpetuated by the state in its failure to address issues of sanitation, housing, and safety, they, too, are a form of biopolitical precarity. The political actions that emerged, as people saw and spoke to the state about their embodied precarity, suggests that there may be value in thinking about these new generation struggles through the lens of diffracted biosocialities. This, then, is the first of the two main conceptual contributions of the thesis.

The second conceptual contribution of this thesis relates to the notion of biopolitical precarity. By developing the concept of biopolitical precarity this thesis argued that we cannot separate the embodiment of medicine from the politics that govern its development and distribution. In doing so, it drew together the sets of literature that have historically concerned either the state of the body (and medical anthropological literature on embodiment and biosociality) or the body of the state (and political anthropological literature on networked governance, imaginaries of the state and citizenship). By drawing on this combined literature, in conjunction with actor networks and assemblages, I developed the concept of biopolitical precarity to denote the intra-action of actants and actors in an assemblage that is networked into people’s embodied precarity. In this respect, it connects to and reflects a long trajectory in the field of medical anthropology that explores the fluidity of boundaries between medical technologies and bodies (Rapp, 2001; Lambert, 2002; Strathern, 2009; Vilaca, 2009). Thus, in contrast with historic conceptions of the bounded body as a slate for inscription (see Douglas, 2003) and the bounded state that is autonomous (Weber, 1984) and that ‘acts on’ these

bounded bodies, this thesis articulated a reading of the body as permeable, and of boundaries separating states/citizens, technologies/bodies, culture/nature as porous.

The failure of the government to provide ARVs to Patricia when she became seriously ill in 2003 is an instance where the body of the state and the state of the body were intimately connected through biopolitical threads that reveal citizens' lives as precariously contingent on the state's actions. Chapter Seven articulated, specifically in relation to new generation struggles, how HIV-positive citizens in South Africa saw and spoke to the state using their cameras, their diaries, and their bodies as they marched for education, for sanitation, for sexual rights. I suggest, tentatively, that there is value in linking these two sets of literature – and research dimensions – in understanding how multiple and intersecting inequalities might become embodied in people's lives beyond my fieldwork's specific focus on AIDS biomedicines. For instance, the example of state brutality by police officers against sex workers who are not afforded any legal protection speaks directly to the nature of biopolitical precarity as one in which certain populations are more at risk of violence by the state than others, and it shows, too, the legacy of state violence across the apartheid and anti-apartheid era as sex workers continue to experience legal, political and socio-economic marginalisation.

In addition to the forms of biopolitical precarity that draw the state into people's bodies, this thesis emphasised, too, the importance of understanding biopolitical precarity beyond the reading of the state-citizen dyad historically proposed by Foucault (1978), and later politicised by Agamben (1998a; 2005). To this end, and by using actor networks (Latour, 2005) and assemblages (Ong and Collier, 2005; Collier, 2009) as conceptual tools, the thesis traced the threads further out from the body to show how the biopolitical actions of the state are affected by decisions made at a regional and global level. It suggested that although South Africa and Brazil may be committed to providing AIDS biomedicines to its HIV-positive citizens, the capacity of the state to import or produce affordable generic medicines is tied into a dynamic global arena where international trade agreements, such as the EU-India FTA, bring TRIPS flexibilities under negotiation and threaten the development of generic ARVs in India, the largest producer of these medicines in the world. Further, the thesis also traced the threads into the body and showed that the boundaries of actants themselves – HIV and ARVs – are porous and co-constructed with the body through their intra-action, even becoming the body, as Thobani's description of his body map attests.

Looking back across this thesis, and summarising the discussion above, I propose that the following five main conclusions can be drawn from this ethnography. First, by tracing the connections of actants out of and in to the permeable body, this thesis moved away from linear arguments that position global and national actors as active perpetrators of structural violence enacted on individuals as passive subjects and developed, instead, a composite narrative through the notion of biopolitical precarity. Second, by illustrating the network of human and nonhuman actants within the body, this thesis demonstrated the overlapping complicity of these actants in the embodiment of biopolitical precarity. Third, in arguing that biopolitical precarity is networked in to the permeable body, this thesis challenged the discursive construction of distance in which policy spaces are conceptualised as distinct and hierarchical, cascading down from global coalitions to national, provincial and local levels of governance. This construction of distance facilitates the distancing of culpability from global coalitions, which include national governments, and reflects, I propose, a discourse of collateral damage in which lives are reduced to numbers, and deaths become side effects of global economic crises. Fourth, the dual character of the new generation struggles drew in these actants and actors across scale, and highlighted the value of paying attention to the shifting biopolitical landscape in South Africa following the height of AIDS activism, when the light turns and the less-visible struggles to navigate life sift to the surface. By considering HIV and ARVs as actants, this thesis looks to their intra-active complicity in generating both risk (viral resistance and side effects) and hope (of a long life) within the body. Further, by considering how people, too, are actors through their social and political relationships in this assemblage, this thesis argued for a calibrated reading of their agency through the notion of diffracted biosocialities. Finally, building on the previous arguments, the thesis challenged the construction of women as passive subjects. In addition to outlining women's historic role in calling on global and national actors to make AIDS biomedicines available to all South Africans, this thesis demonstrated how women also subvert hegemonic development subjectivities in order to strategically anchor their lives along the knife-edge of precarity. In sum, this thesis was about women's lives linked to HIV and AIDS biomedicine, but it was also about more than this: it was about how their vitality is inextricably linked to the governance of technology and the technologies of governance.

9.3. Methods and Concepts: Limitations, Contributions and Potential Developments

I wrote in the introduction that the people with whom I worked were the starting place of this ethnography; the way that they each looked to the future, and made sense of their present by remembering their past, is the core thread of this thesis. The iterative sedimentation of these accounts in the course of my fieldwork presented a complex task for writing this thesis: I did not want to 'make sense' of their 'sense-making' by separating out and examining these inseparable threads as though I knew, better than they did, how they fit together. In order to work against this way of 'sense-making', I sought to develop a methodological and conceptual approach that would enable me to trace connections (and not dislocated distinctions) across time-space and the permeable boundaries of the body of the state and the state of the body. I reflect on these approaches below.

First, looking at the 'logic' of my thesis structure, it might have also worked to build the ideas of Anamnesis and topologies into all five ethnographic chapters, and not only into the Chapter Six. These are powerful concepts and they were valuable for finding a way to articulate the shifting accounts of women's lives; like Zama's brown map, these recollections of home, of the risk and the romance of the Eastern Cape, were present and held in women's bodies. These recollections also fell away like the flakey imbrications of a snake's shed skin, and then resurfaced at other times, depending on the spaces in which the women were located in their own lives and in the course of my fieldwork with them. During my fieldwork, I had been quite certain that this thesis would be built almost entirely around theories of space (this connects, too, with the second alternative way I had thought about building a digital thesis using mapping software). However, when I started to work through my field notes, and all the digital, social and journey maps that we had made, I found that this approach did not sufficiently 'get at' the complex network of relationships I had observed in my ethnography; nor did it offer scope for critiquing the implications of this network on women's embodied experiences of precarity linked to the new generation struggles that I had observed. I focused, therefore, on building the overarching argument I made across this thesis, that biopolitical precarity is networked into the permeable body.

Further, when I turned to research the field of space for Chapter Six, I realised that my own thinking was out of date. I had been dazzled by Lefebvre's (1991) trailblazing work on the production of space before starting fieldwork. When I returned, however, I needed to make

sense of the way I had seen space both produced and embodied, in part through shifting recollections, in my field sites. Working across my field notes and theory, I learnt that there was a slew of cutting edge feminist (Rose, 1993, 1999), queer (Gren, 2001; McKittrick, 2004) and science studies (Mahler and Pessar, 2001) theorists who had taken this field of study even further forward. In contrast, there was very little social science work on Anamnesis. There were, however, some studies by medical anthropologists (see Mol and Law, 1994) that argued for the importance of integrating topologies with actor networks and illness narratives. Compelling as these emerging approaches to space and Anamnesis were, I was concerned that tracing them across the thesis would dislocate the main ethnographic argument and add unnecessary complexity. For this reason, I explored Anamnesis and topologies in the central ethnographic chapter only. It is perhaps, for these combined reasons, that I am most interested in taking the theory and argument I developed in Chapter Six around memory and space into the future work that I will be doing on biopolitical precarity linked to the law, citizenship, gender and sexuality. I found this set of approaches productive in making sense of everyday life, and the strategies we use to navigate the spaces and times through which we walk, talk, think, love and live.

Second, in the conceptual framework I wrote that I have necessarily organised a multi-sited ethnography into a linear structure, but the framework could perhaps have benefited from a three-dimensional contraption that articulated these same arguments but that was more interactive. I had hoped, when looking at the digital data I had collected during my fieldwork, that I could perhaps communicate this 'matrix-structure' electronically by building a thesis on an electronic platform (through a private website that used digital mapping software). This, however, was not possible. Perhaps, too, this has meant that I have needed to think harder and more carefully about the conceptual framework and the overall structure of my thesis. It was the conceptual framework that ultimately would hold – and hopefully has held – the shape of my ethnography.

In my future work, I hope to integrate the visual research methods I used in my thesis with digital media for two reasons. First, the images and stories of the women I worked with had taken on 'social lives' through their use in *uYaphi's* website, in the global Body Map exhibitions, and in numerous activist and academic publications, for example. The women were not entirely comfortable with the extent to which these images of their lives were used; they had in most cases given full consent (although this was not always clear), but the almost infinite use of these images for purposes that the women had not consented to was

fundamentally problematic (Thomas, 2008). It also illustrates the argument I made in this thesis, that women's lives become, with time, increasingly distant and dislocated from the centres of power (like activist organisations, NGOs and governments) that rely on these women's bodies, their testimonies of precarity, to garner support and bring in resources. I have, for these reasons, been cautious about the images I have used, and I have sought to reflect the lives of the people I worked with as carefully and accurately as possible. Visual methods, as I discuss below, were a part of my attempt to co-construct an ethnography of mutual accountability, where we entered each other's lives and shared the information we were comfortable with sharing in the course of our relationship. By working visually, together, on digital platforms (increasingly accessible technologies like Whatsapp or even Google maps), I believe that it would have been even more possible to ensure that the women consented to the way I conveyed their stories.

Second, this alternative (and perhaps unsuitable) approach to creating an electronic thesis, speaks to a deeper concern I have about the authority academics hold over the way narratives are constructed; we consider our positionality and accountability when doing our fieldwork, but perhaps less so when we analyse and write up our field notes. As concluded above, I developed the concept of biopolitical precarity to argue for an ethics of accountability where we call global actors to account for the extent to which their actions are embodied at the most intimate level in people's lives. At a conceptual and methodological level, in writing this PhD, I have been aware, too, of my responsibility and accountability to the multiple actors with whom I worked. In carefully creating (hidden and public) digital platforms for future work, I would like to explore alternative ways of creating academic narratives in conjunction with people and organisations with whom we work, and to whom we are accountable.

As discussed in the methodology chapter, this thesis broadly reflects one of two prevailing approaches to studying health and politics in anthropology: the first approach concerns biopower and subjectivity and is held against the second approach, the politics of identity (Whyte, 2009). In her discussion and critique of the relative contributions and limitations of each approach, Whyte (2009) advocates an extension of multi-sited ethnography through comparative ethnography. Although my research concerned biopower and health, and I conducted research in Brazil and South Africa, I did not conduct a comparative ethnography. I therefore reflect on Whyte's critique as a lens through which to explore the relative limitations and contributions of 'connective' multi-sited ethnography as the methodological approach underpinning this thesis.

As we saw in this thesis, and in the cases of Gabriela and Ronaldo in Chapter Eight, an individual's plural identities run alongside a collective's strategic mobilisation of one salient identity – disability, leprosy or HIV; and as Whyte and Muyinda note, this mobilisation reflects “current paradigms for health and development that emphasize the ‘rights-based’ approach” (2007: n.p.) and, in each of these cases, has facilitated access to international and national resources. According to Whyte (2009) the second approach, namely biopower, has been used by ethnographers like Petryna (2006), Biehl (2005) and Ngyuen (2005, 2010) to place health identities in a global context of transnational connections. Whyte critiques both of these approaches, and writes that, “There is a danger that we lose sight of the political and economic bases of health in our concern with identity, recognition, and the formative effects of biomedical and social technology” (2009: 12). Rooting Marcus's concept of multi-sited ethnography in these contemporary reflections on subjectivity, Whyte (2009: 15) advocates comparative ethnography as way to move out from a narrow focus on health in order to anchor people's lives in their social, economic and political relations.

Whyte (2009), and more recently other anthropologists like Marsland (2012), Prince (2012), Le Marcis (2012) and Fassin (2013), have reason to caution researchers like myself against narrowly defining their research field before they enter the field itself. If we go into fieldwork with a set of expectations about the kind of people we will spend time with, and the kinds of lives they live within these narrow framings of illness and health, then I think it is likely that we will find what we are looking for, and we will miss most of what is actually happening around us.

I did not want to fall into this trap. Yet I was not quite sure how to work against this – against slipping into labels – while still keeping the focus of my research in place. As I wrote in the methodology chapter, I aimed to work with women who had been activists, and who were on ARVs, and who lived in Khayelitsha; these criteria were important, initially, for me to start looking at the links between the politics of citizen engagement (as activists) and women's embodied experiences of medicines (on ARVs). I could not look at these two dimensions of my PhD without this very basic set of criteria. However, these criteria – these labels – quickly slipped under the surface of far more complex relationships that were not about illness, or even medicines, but about figuring out ways to let each other into each other's full worlds. It became, quite actively on all of our parts, a year of hanging out and working to get past these labels. I therefore needed to draw on methods that were much more about sharing our lives,

than they were about extracting stories and leaving the women behind in Khayelitsha as I move forward with my unquestionably privileged life in Brighton. As stated above, this is part of the reason I used visual methods, like participatory photography. This component of my fieldwork generated over a hundred gigabytes of data, and many hours of conversation; I have used very little of this material, but I could not have written texture into this thesis without these visual conversations. They were essential. If possible, when I have completed this PhD, I would like to find a way of working with this group of women to curate an exhibition of our photographs, and to make a documentary using the digital material in which we saw and spoke to the state.

Whyte (2009) suggests that comparative ethnography is one way that we can move beyond the limitations of too narrow a focus on illness identities in health research. For this ethnography, I did not believe that it would be possible to establish sufficient similarities between my field sites in Brazil and South Africa to validate any claims I might make through six months' ethnography in each site; further, without a full grasp of Portuguese, my ethnography in Brazil would be far thinner than my ethnography in South Africa. With these limitations in mind, I instead conducted a multi-sited ethnography that is anchored in South Africa, but that sought – through research with actors that span local, national and international fields – to locate South Africa and the lives of the people with whom I worked in a global terrain. Through my fieldwork I sought to trace connections rather than to make comparisons. This was an active decision, and perhaps opens me up for criticism, as it is also an unusual choice to conduct a substantial amount of fieldwork in one place, and a significantly shorter period of fieldwork in another. However, I believe that this approach enabled me to make the argument I built in this thesis – it enabled me to show, concretely, how women act in and through a global assemblage of actors and actants to secure their vitality; further, it enabled me to trace the implications of this assemblage back into women's lives as they embodied multiple forms of biopolitical precarity linked to, and extending beyond, access to AIDS biomedicines.

9.4. The Right to a Nonprojected Future

The possibility of death ran across my fieldwork like a quiet underground water source that very rarely came to the surface. When it did surface, it was always unexpected. I started this thesis with a vignette of Miriam's life and the threads that link her vitality into the pills in the tubs on her dressing table, outside and into the muddy street with the single tap that provided

water to her home, across the city and into MSF's offices where I learnt, with her, that she would not have access to third line treatment when and if she developed resistance to her current treatment regimen.

As I come to the end of this thesis, Miriam has just given birth to Alizwa. She told me over the phone's crackling static that Alizwa meant 'God has given me another girl'. You may recall that she has a daughter, Nena, who was born in the 'window period' before the government provided medicines to block HIV from moving along vertical pathways from Miriam's body into her daughter's body. Now, in 2013, Miriam's activism to bring PMTCT into South Africa has meant that when she went into labour, she was able to access nevirapine to protect her second daughter from contracting HIV. I saw Miriam just before she had her baby; she was about eight months pregnant and she had such swollen feet that it was very difficult to walk. Sitting on the beach after lunch, the quiet rippling thread of threat rose to the surface of our conversation. She started speaking without words, squeezing my hand. I turned to her. She said, "Beth. What if." I pretended I did not understand, and said, "What if what, Miriam?" She laughed at me, letting me know that she could see that I knew what she was talking about. "What if these stupid pills stop working? What happens then?" Just as I had no words for her when we spoke after my meeting with MSF almost three years previously, this time on the beach, we sat without words and looked out at the horizon over the sea together. Later in the car on the way home we took a bet on when her baby would be born and Miriam said, "Ya, but you won't be here then, will you? ... Anyway, when you come back, you will meet her. And me. You will see me too; I'm not going anywhere sana." With that, we said goodbye.

10. Reference List

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